CREATING KIDNEY SUPPORTIVE CARE PROGRAMS: LESSONS LEARNED AROUND THE WORLD

A report from
The Coalition for Supportive Care of Kidney Patients

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EXECUTIVE SUMMARY

The Pathways Project, funded by the Gordon and Betty Moore Foundation, is designed to develop a package of evidence-based practices to deliver supportive renal care, including medical management without dialysis. Recognizing that programs in other countries potentially have best practices to share, we interviewed 17 programs, 5 of which were in the US. Conversational interviews were conducted by phone by one interviewer.

We identified critical success factors through the interviews; these included education, communication skills, fostering collaboration, and finding champions. Barriers were also identified and included cultural attitudes, lack of resources and time, and a lack of strong evidence.

Models of care among nine programs are highlighted, and while there is agreement about the content of care (symptom assessment and management, advance care planning, coordination with palliative care), there is little formal testing of administrative, staffing, financing, and organizational components.

While conducting the interviews, the common elements of kidney supportive care provision emerged. There was an emphasis on protocols and routines that included the use of checklists and algorithms. Communication and care planning drew a distinction between goals of care discussions, electing and understanding values and preferences, and shared-decision making. Mechanisms to address symptom assessment and management, supporting dialysis options, decisions to stop dialysis, and acceptability of supportive care for dialysis patients were offered.

Likewise, common elements of medical management without dialysis (aka “conservative care”) were explored. One change made to implement a medical management without dialysis program was conceiving of it as a cohesive treatment modality, rather than simply “not doing dialysis.” Helping patients and families learn about the medical management without dialysis option through carefully developed decision aids, educational material and websites was emphasized. The language in these educational materials, as well as the language used by staff, was important in conveying the message that medical management without dialysis was active management, and was not “doing nothing” or abandonment by the nephrology team, as some patients feared. Finally, symptom management, care planning and planning for end of life, were also addressed by medical management without dialysis programs.

Several contributors discussed their motivation for engaging in kidney supportive care. Often contributors recalled an early experience with a specific patient as a motivator to establishing palliative care approaches. Sometimes it was an encounter with a patient who declined to start dialysis. Other times it was unaddressed suffering or observing the trajectory of the patient’s experience.

In summary, there was striking agreement as to the components needed to deliver kidney supportive care, including medical management without dialysis (aka conservative management), even across the five different countries in which the respondents practiced. The common components included

- Appropriate patient identification
- Communication, advance care planning, and goals of care conversations
- Symptom assessment and management
- Collaboration with palliative care
- Early referral to community resources such as hospice

Despite the consistencies identified, the way to deliver care had many variations and adoptions arose from local circumstances. The amount of variation and lessons learned gives rich opportunity for future implementation and research.

METHODS

PURPOSE OF PROJECT

This report was prepared as part of a project to develop a package of evidence-based practices to deliver supportive and conservative renal care. It was designed to supplement the formal literature review conducted as part of the larger project. While the formal, indexed, and peer-reviewed literature presents research results and guidelines, it mostly lacks detailed implementation guidance. We sought to supplement the formal literature review with interviews designed to gather practical advice from clinicians with experience implementing supportive care programs. The goal was to gather the “lessons learned” over the past decade-plus.

Interviews were conducted by phone by one interviewer in a conversational manner. An interview guide was prepared, but the interviewer departed from the guide as needed to explore the particular experience and expertise of each respondent.

PROCESS FOR SELECTING EXPERTS TO INTERVIEW

The list of experts was compiled by asking members of the project’s Technical Expert Panel for suggestions of clinicians thought to have relevant experience delivering supportive and conservative kidney care. Emphasis was placed on interviewing experts outside of the United States, since it was known that supportive care is more widespread in Canada, Australia, and the United Kingdom. We also used a snowball technique by asking each respondent if they had suggestions for additional people with whom we might talk.

DESCRIPTION OF EXPERTS INTERVIEWED

Most respondents were from countries other than the US. Seven worked in the United Kingdom and five in the United States. (See Table 1) Most (12) were physicians. Other professions included three nurses, a psychologist, a social worker, and an administrator. Most were nephrology specialists, although five had palliative care expertise. One respondent was counted as having expertise in both nephrology and palliative care.

FINDINGS

CRITICAL SUCCESS FACTORS – TABLE 2

Respondents had strong opinions about factors that fostered successful implementation of supportive nephrology. The most widely mentioned was education for providers, both in symptom management and in communication skills. Several programs have invested considerable resources in developing curricula and training programs and in offering them regularly. Most programs reported that their training programs were well-attended. Education was seen as important for current staff as well as for fellows and trainees. Further, education was perceived as key to changing the culture of nephrology, which was identified as one of the major barriers.

Another success factor was fostering active collaboration between nephrology, palliative care, and, sometimes, primary care. This was related both to education – in the sense that the nephrology staff spoke about how much they learned from palliative care staff and vice versa – and to coordinating the services of the nephrology and palliative care teams. For instance, nephrology often relied on palliative care to provide the 24/7 back-up in cases of urgent/emergent needs. Many services introduced the palliative care team early on – "just in case you need them later" – often with a joint visit. Some respondents also described a three-way collaboration among primary care, nephrology and palliative care. Others operated mostly in the context of nephrology-palliative care cooperation.

Finding champions to lead the work was recognized as important. While a nephrologist champion was always needed, many respondents noted that nursing played a critical leadership role in fostering change. These leaders were key in changing culture throughout the nephrology continuum. Finally, additional success factors included having the research, data, and professional guidelines to show that supportive care and medical management without dialysis were effective. One respondent summed up her view of success factors this way:

> "Common features seem to be identifying people who can lead the work, identifying the training needs of the wider nephrology team, putting in place some guidelines or some resources around symptom management, and beginning to raise awareness among the team that some of these patients are quite close to death, maybe in the last year of life, and then they need to really address some of the issues." (Respondent 1)

BARRIERS TO SUCCESS – TABLE 3

Barriers to success (see Table 3) ranged from broad cultural attitudes toward death to very specific economic and regulatory issues. General cultural reluctance to discuss death was mentioned as impeding open discussion, especially in Northern Ireland and the southern United States. The particular culture of nephrology – which has become centered around technology and dialysis – was mentioned numerous times as a significant barrier. Many respondents expressed a sense that it was often older colleagues who were entrenched in an approach hostile to medical management without dialysis or palliative care, while trainees were eager to learn new approaches.

Economic incentives for dialysis were perceived as having a strong impact in the US. In other countries, the incentive to provide dialysis was not as strong. But, even in countries operating health services on a national or regional budget, there was difficulty obtaining the financial and staffing resources to provide supportive care. Lack of resources to implement supportive care, lack of time to spend in family discussions, and a sense that palliative care staff might be diverted to the perceived "higher" priority of providing dialysis were all cited as impediments. Finally, the lack of a strong evidence base was cited many times as a barrier, both in convincing colleagues and in providing patients with information they need to make decisions.

MODELS OF CARE – TABLE 4

A wide variety in the organization and models for delivering kidney supportive care was noted. Some programs obtained additional funding, while others reallocated existing resources. A major source of variation was in the way that specialty palliative care was integrated – or not – into the renal service. One respondent who has surveyed all renal units in the United Kingdom categorized the variations in practice as renal supportive care

- Driven by palliative care specialists, but then supported by renal teams
- Jointly provided by palliative care and renal
- Provided by an individual within the team who has received a little bit of training, likely without any extra funding

Efforts to educate and "skill up" the renal staff with additional palliative care expertise (notably symptom management and communication) were commonplace. Sometimes this took place through the presence of a palliative care specialist in the renal clinics. Sometimes formal training programs were conducted. At least one respondent felt it was essential to have a strong palliative care presence WITHIN the renal team, rather than just referring to palliative care.

Two formal protocols for delivering supportive and/or medical management without dialysis were found. The first, "Prepare for Responsive Management," is the protocol for the conservative care intervention in a randomized control trial underway in England. This protocol uses a care coordinator to deliver conservative care at home in three phases as patient/family needs escalate:

1. Assess: commence home visit(s) (up to 3 within 6 weeks) to assess needs and develop a care plan. The first visit includes a comprehensive advanced CKD care assessment to generate an agreed-upon personalized problem list and action plan. Advance care planning is also conducted in this phase.
2. Responsive Management: Monthly phone contact; Provide home visits alternating with clinic visits to regular nephrologist. ~2-4 monthly review at home or clinic.
3. Supportive care: If the patient develops symptoms of advanced CKD that cannot be adequately controlled they progress to the supportive care stage. The advance care plan and any other documentation relating to priorities for care must be reviewed and the appropriate local community and palliative care services activated and coordinated to achieve good end-of-life care. This must be done rapidly to prevent inappropriate default "cure-centered" care being administered in the event of a sudden deterioration.

The second formally specified model was the Conservative Care Pathway developed by the British Columbia Provincial Renal Agency. This model specifies the elements that need to be delivered once a patient has chosen conservative care:

Phase 1c: CKD Stage 5 Care (ESKD) (ongoing supportive care, eGFR <15)

- Includes communicating patient's modality choice with patient's primary care physician, advance care planning, goals of care discussion, comprehensive symptom assessment and management, medication/blood work rationalization, and crises education and planning

Phase 2: Decompensation (life expectancy: <8 months) (declining eGFR and symptoms that would otherwise have triggered RRT if the conservative care path had not been chosen)

- Includes communication with PCP and other patient supports (e.g., home care and/or palliative care team) re: significant changes in patient status, continued discussion regarding current care plan, including goals of care, referral to palliative care team, and comprehensive symptom assessment and management

Phase 3: Increased Symptoms (life expectancy: <1 month) • KCC team available to PCP and hospice/palliative care teams for consultation (mostly symptom management)

Phase 4: Decline/Last Days • KCC team available to PCP and hospice/palliative care teams for consultation (mostly symptom management)

Phase 5: Death & Bereavement • Bereavement support. • Reflecting upon the patient's death as a KCC team

While there appears to be a great deal of agreement about the content of the care that needs to be delivered (symptom assessment and management, advance care planning, coordination with palliative care, flexible and home-based care), there has apparently been very little formal testing of administrative, staffing, financing, and organizational options. One informant noted that they had found their conservative management nurse could handle a caseload of about 50 patients. Respondents noted that variations in the availability and scope of local palliative care services strongly impacted the way that medical management without dialysis could be provided, especially toward the end of life. Partnership with primary care providers – the extent to which they felt comfortable managing renal disease – varied considerably as well.

One respondent is in the early stages of using a geriatric assessment model and felt this approach held promise for improving aspects beyond symptoms. Their preliminary data based on screening all older patients for frailty and dementia has led to improvement in satisfaction scores and distress thermometer scores and a reduction in hospital lengths of stay.

COMMON ELEMENTS OF KIDNEY SUPPORTIVE CARE PROVISION – TABLE 5

Across a variety of different settings and models, respondents identified common components that they had found to be useful in providing kidney supportive care. These elements are described in Table 2 and include

- Goals of care conversations
- Advance care planning process
- Advance care planning documentation
- Engagement of family in care planning
- Symptom assessment and management
- Screening and referral for specialty palliative care
- In-home care services
- Palliative dialysis and other non-standard dialysis options
- Dialysis withdrawal process
- End-of-life support
- Outcome measures

PROTOCOLIZING AND ROUTINIZING CARE PROCESSES

While these elements of care may be found in routine nephrology care, the respondents often expressed that they were now bringing more concerted attention, resources, and expertise to the issues. Respondents described using checklists they had developed, algorithms for symptom management, and informal protocols to make sure that a variety of patient needs were addressed. Using standard, routinized protocols that made the above elements an expected part of care processes was transformative. Elevating attention to symptoms, patient experience, and patient goals to the same importance as blood chemistry changed practice and outcomes:

> *One is that as a nephrologist I thought I was doing it, so I… still take pride in thinking that I'm taking a holistic approach to my patients and so forth. And I have to be honest, it was only when we really got stuck into this program did I realize how many symptoms I was missing. The patients, they don't want to bother me with it because they can see I'm busy, running a busy clinic, and you know I ask them how are you doing and they'll say just "I'm fine." And symptoms? "No, I'm, good." Whereas that same patient when they're filling out the IPOS symptom survey in the waiting room before the renal supportive care clinic, they might have seven or eight symptoms.* (Respondent 13)
>
> *It took a while for me to gain confidence with letting go of biochemistry, as a nephrology nurse. I had never trained in palliative. I was naturally very focused on, okay, your eGFR is now eight, and your urea is 25. But what palliative care specialists taught me was to have confidence with your clinical assessment of symptoms, not just biochemistry.* (Respondent 3)
>
> *That's the formalized routine integrated into not only the culture but the actual function of the clinic. When you walk in the door, the receptionist says, "Hi, Mr. Jones. Nice to see you again. Come on over here. We're going to take your weight. Here's the symptom form. Can you have a seat…". It's very much protocolized. Symptom assessment and inquiry are part of the care. Then I would say having skill at managing those symptoms in renal patients is obviously really important.* (Respondent 14)

COMMUNICATION AND CARE PLANNING

Many of the processes and tools discussed related to discussion and communication with patients and families. We categorized goals of care discussions, shared decision-making to choose care options, and advance care planning into separate categories, even though respondents often described overlaps among these practices. The distinction is that goals of care discussions cover broad discussions for eliciting and understanding patient and family values, desires, and preferences for care. Shared decision-making then uses that understanding for the specific task of deciding on a course of care (e.g., dialysis vs. medical management without dialysis) that requires both input from the clinician (about likely prognosis, likely risks and benefits of alternative treatment courses) and from the patient/family (about their values and preferences). Advance care planning is the subset of planning that looks to a time when a patient may not be able to make his/her own decisions and will need someone else to make decisions on his/her behalf. Advance care planning also includes documenting patient choices so they are actionable at a future time.

Components of goals of care discussion discussed by respondents included

- Engaging in discussion with patient and family to find out their preferences and goals.

- Documentation of goals.
- Some use a formal guide; others conduct very individualized conversations.
- Varies as to who conducts the conversation. Usually nephrologist involved. Nurse may also be part of it. Team effort.
- Prognostication is necessary part of goals of care discussion process.
- Implementation of services to meet patient goals takes many forms.
- Development of detailed plans to meet patient goals, including plans for end of life.

Key aspects of the advance care planning process included

- ACP discussions held as routine, regular part of care.
- ACP discussions appropriate BEFORE starting dialysis.
- Who conducts ACP varies by settings. In some places it is the social worker, in other places the nephrologist.
- ACP part of a continuing set of discussions, not one time filling out a form.
- ACP often intertwined with process of choosing whether or not to start dialysis.
- Use consistent process for formal documentation of wishes that meets legal requirements or guidelines.
- All providers know where to locate information in EMR, or in a folder, or on the refrigerator.
- Need to engage caregiver in ACP discussions. Family empowerment important in following ACP wishes.

While conceptually we see a distinction between broad goals of care discussions, shared decision-making, and advance care planning, in practice, these may fluidly overlap. What was distinctive in the processes described by respondents was that providers made it a goal to have the time to conduct these conversations with all (or most) patients in a proactive manner, rather than leaving it for the patient to initiate.

> *We included advanced care planning as part of that discussion. I created an extra box in my form called "advanced care planning." So that's when I had the discussion. And it's not a very formal discussion, you know. It just leads from talking about how they're coping with dialysis and reviewing their clearances and thinking about is personal directive working for them or should they be thinking of something else to what their wishes would be. And I'd be recording that. And often the statement that I'll usually record, and I always read it back to the patient. So I always mention who was with them. You know like a wife, brother, friend, whatever. "Patient has decided that ... if very ill, no longer independent, poor chance of recovery or either future independence, does not want to linger in death..." I use their words. "Wants a dignified end." "Does not want to be a vegetable." I always put that bit into inverted commas. And then I repeat that each year. And obviously as things progress, the conversation can become more detailed. So I don't mention resuscitation the first time around.* (Respondent 9)

SYMPTOM ASSESSMENT AND MANAGEMENT

In addition to clear and routine communication about goals and plans, many emphasized the importance of meticulous attention to symptoms. Symptom management was described as including both routine assessment using validated tools and management of the symptom following algorithms or guidelines. One respondent emphasized the helpfulness of algorithms in working with the general practitioner to provide ongoing management of symptoms, including pain. One respondent noted that symptom management did not take as much effort as expected:

> *I thought it would be a lot of symptoms, but it hasn't been. It's really been a lot of advanced care planning and care planning and a lot of discussions about goals and trying to figure out what people want and ensuring that their care is in line with those goals. Education about what to expect as your kidney disease progresses, what are the symptoms to anticipate, and then giving people some tools to deal with them in a non-pharmacologic manner, and if they choose, to offer them medications, to treat them.* (Respondent 12)

Even so, several respondents noted that escalation in symptoms toward the end of life required capacity to respond quickly and appropriately:

> *Actually, they may be relatively asymptomatic of uremia but patients managed conservatively without dialysis can deteriorate very rapidly. This means you need to meet them much earlier on in their illness trajectories in order to anticipate that "tip." The clinical implications are that you need to have a responsive and flexible service for this group of patients.* (Respondent 3)

SUPPORTIVE DIALYSIS OPTIONS

Flexible modification of standard dialysis routines was used to adjust treatment to patient goals. The number or duration of dialysis sessions was sometimes modified to meet patient preferences. Especially in the case of peritoneal dialysis (PD), patients and families often wanted to continue treatments through the end of life because they were perceived as not very burdensome and providing some symptom management benefit. Assisted PD could be continued when a patient changed setting (such as entering inpatient hospice).

Forthright planning for the end of life, including stopping dialysis, was seen as a key part of the supportive care process. Knowing where and how a patient wanted to be for the end of life was part of earlier goals of care and advance care planning discussions. The capacity to make good on patient wishes had several elements: knowing those wishes, communicating the plan effectively to everyone involved across treatment sites so that there wasn't pressure to accept or continue with unwanted treatment, and close coordination with palliative care/hospice to handle the logistics and support for the last weeks/days. One practitioner found that proactively establishing "ceilings of care" was helpful, especially in the case of helping family make decisions about stopping dialysis for patients whose dementia had progressed. Home visits, either jointly to introduce the palliative care team or for purposes of planning and care delivery, were seen as an important element of successful care.

STOPPING DIALYSIS

Decisions to stop dialysis were treated as an expected part of the trajectory of care. The keys were respecting the patient's right to make this decision, helping family be part of the decision, and bringing in palliative care/hospice to help with the transition.

> *For dialysis withdrawal, we've actually not been doing too badly. We've established a process so they don't actually have to go to the hospital. If a person starts expressing that they're tired and they don't know if they can do this anymore, we have people who are*

> *willing to talk to them and then we get the palliative and hospice team involved and then the person doesn't even have to go to the hospital. It's all done through the dialysis unit and then they palliate at home or in residential hospice.* (Respondent 12)

ACCEPTABILITY OF SUPPORTIVE CARE FOR DIALYSIS PATIENTS

In summing up his own successful efforts to develop and spread kidney supportive care, one respondent advised that it was easier to change nephrology culture by starting with improving supportive care for existing dialysis patients, rather than by first establishing a medical management without dialysis pathway:

> *From all of that experience, I think that, first, things were shining on the nephrologists that their dialysis patients benefit from this approach, before trying to get them on board about the conservative nondialysis pathway.* (Respondent 13)

COMMON ELEMENTS OF MEDICAL MANAGEMENT WITHOUT DIALYSIS – TABLE 6

Medical management without dialysis shared many characteristics with kidney supportive care of patients receiving dialysis treatment. Some respondents emphasized that it was important to patients to know that they would be actively cared for, that medical management without dialysis was not "doing nothing." These respondents noted that patients were reassured that they would continue to see the nephrology team, that symptoms would be addressed, and efforts to slow disease progression could be continued. The language and messaging about medical management without dialysis as an active option were seen as important to its acceptability.

In addition to messaging, most of the respondents had also established formal pathways or protocols for providing medical management without dialysis. As discussed under models of care, there was variation as to how these were staffed, whether all nephrologists offered it or patients were referred to a particular nephrologist designated for medical management without dialysis, and the ways in which consultation and collaboration with palliative care was provided. Despite these differences, a notable shared characteristic was that this was a change from the way care had been provided in the past, sometimes despite concern or even opposition by other nephrologists or staff. The new approach to medical management without dialysis involved formalizing the selection and designation of patients who desired such care, honoring patient preference—even as those preferences might change, and delivering care that aligned with patient goals.

The specific elements of the medical management without dialysis pathway included

- Identifying appropriate patients
- Clear tracking of patient modality (sometimes through a registry)
- Shared-decision making using unbiased educational materials or decision aids
- Messaging and education about medical management without dialysis
- Symptom management and support for quality of life
- Care planning and continuing care management
- Careful, planned transition at end of life, in collaboration with palliative care/hospice

IDENTIFYING AND TRACKING MEDICAL MANAGEMENT WITHOUT DIALYSIS PATIENTS

One of the distinctive changes made to implement medical management without dialysis was clearly conceiving of it as a cohesive treatment modality and overtly identifying patients who had chosen this type of care. This contrasts with prior practice when any patients not on dialysis were viewed as “pre-dialysis” with the expectation that they would most likely eventually progress to dialysis – whether by plan or by necessity. The labeling of these patients as “pre-dialysis” sends the message that everyone will eventually choose dialysis, whereas changing the language to offer conservative management as an option of equivalent clinical importance as hemodialysis or peritoneal dialysis helps both staff and patient respect and implement an appropriate plan for the patient. One respondent noted that they group patients into three groups: those who have chosen dialysis, those who have chosen conservative management, and those who have not yet made a decision.

Identifying appropriate patients for conservative management involved three steps: 1) identifying patients who might be expected to fare poorly on dialysis by using various measures for frailty or co-morbidity or prognostic indicators, 2) educating patients about their options (including medical management without dialysis), and 3) engaging in shared-decision making to help patients align care with their individual preferences and goals. Providers counseled that it was necessary to confirm that referrals to medical management without dialysis were understood and desired by the patient:

> *We early on just accepted a referral from a nephrologist or one of the nurses but what became apparent is that they perhaps thought they communicated with the patient and their family but what the patient took away from there wasn't clearly that they were choosing not to do dialysis. That's why we actually insist that they have to go and have the proper education and listen to the different options that are available, and then at the end of that make a decision.* (Respondent 12)

Once patients have chosen a conservative management option, sites had various ways for communicating that status with all parties. Some used electronic registries that could be accessed by any provider or hospital. Others used low tech solutions such as a paper on the refrigerator or a folder in a “green sleeve” that the patient was instructed to take with them to the hospital. The key point was that there was clear communication with other providers so that they could respect patient/family choice and not put undue pressure on them or make assumptions about using dialysis as a treatment mode. If such information was NOT communicated, respondents often encountered a change of course made in response to urgent symptoms, perhaps ones that could have been handled via more robust palliative care:

> *Then you'd come in on the Monday, and quite typically someone had been admitted as an emergency on the Saturday, a nephrologist had come along and said, "Look, you're gonna die if we don't put a line in and dialyze you". There were some patients who had made the decision not to pursue dialysis, who then became symptomatic of their renal disease and/or co-morbidities. If they weren't backed up by palliative care services, they would end up being admitted to the renal unit and dialysis commenced. Whilst there are clearly some patients in whom it’s the right thing to revisit and commence dialysis, in some patients it’s palliative care, good symptom assessment, management, psychological and end of life care they need.* (Respondent 3)

SHARED DECISION MAKING

Several sites have put extensive work into developing decision aids, educational materials, and websites to help patients and families understand the option of medical management without dialysis. Respondents noted that the readily available patient educational tools had very limited information about medical management without dialysis and were often subtly or overtly biased against that option:

> *I came from a health psychology background where I understood that patients are not doing nothing. They're actively managing their kidney disease. That is an active kidney option. An active treatment option. It was very clear to me from my perspective. It was not doing nothing or not having an active option. But how do you raise the profile of the conservative care option so that it was equivalently active? That's where my decision-making side came in. Because I was very aware that the language that was used was very biased and switches people off.* (Respondent 7)

In describing their effort to develop a decision aid conforming to the principles for decision aids, one respondent said, *"It's very clear from our research that the decision between conservative care and dialysis is a very different type of decision [than] the one when you are choosing between treatment options. It requires a very different approach."* (Respondent 8)

The process of engaging patients in shared decision-making varied. Some sites had standardized presentations and relied heavily on nurses to provide the education component. At other sites, nephrologists were heavily involved, although even within the same site this reportedly varied from nephrologist to nephrologist. What was constant was providing patients with information customized to their situation, including prognosis, ample time to draw out patient and family values, and an attitude that respected patient choice. Most respondents expected some patients to change their minds, and were surprised that far fewer than they had expected ending up switching from medical management without dialysis to dialysis.

MESSAGING AND EDUCATION ABOUT MEDICAL MANAGEMENT WITHOUT DIALYSIS

Respondents were thoughtful and careful about the language that they used related to medical management without dialysis. They found that it was important to convey that medical management without dialysis was ACTIVE medical care even though it did not use the dialysis modality.

> *The enormous care I have when I use language with patients - And I'd like to think that has also filtered through to the team and the pre-dialysis nurses are now very, very good at getting that decision right, particularly for conservative management.* (Respondent 8)
>
> *I came from a health psychology background where I understood that patients are not doing nothing. They're actively managing their kidney disease. That is an active kidney option. An active treatment option.* (Respondent 7)

They also stressed that involvement of palliative care practitioners was not because death was imminent, but because it could positively support better quality of life. Old habitual language such as "you could do nothing" was dropped in favor of language that emphasized weighing burdens and benefits and selecting a pathway that best achieved the patient's goals of care.

SYMPTOM MANAGEMENT AND SUPPORT FOR QUALITY OF LIFE

Effective symptom control was a major part of the medical management without dialysis pathway. Many of the same symptom assessment and management approaches described herein for supportive care were also used in the conservative management approach, although respondents emphasized the need to tailor approaches such as phosphate binders to the patient’s goals and concerns.

> *A lot of time is spent on investigation and medication rationalization. Some people call this de-prescribing, but what we try to do is go through all the medications that a person is on and figure out if they actually are in line with the person's goal. And then the investigation: rather than just having standing lab tests, what are the person's goals and are these lab tests in accordance with what the person actually wants?* (Respondent 12)

As they gained more experience with medical management without dialysis, respondents expressed surprise that many patients could maintain relatively good quality of life for long periods. However, the “tip” to a highly symptomatic state could be quite sudden, requiring a rapid palliative response.

CARE PLANNING AND CONTINUING CARE MANAGEMENT

The period of medical management without dialysis provided an opportunity to put proactive plans in place to support quality of life. Most respondents saw patients on a regular schedule (often monthly) in their clinics until they were no longer well enough to come in, at which time home visits might be initiated.

> *It's really been a lot of advance care planning and care planning and a lot of discussions about goals and trying to figure out what people want and ensuring that their care is in line with those goals.… A big part of what happens is really reviewing goals and choices, making sure that their resuscitation status is documented and the appropriate forms are filled out, making sure that there's a crisis plan in place and that there's time to do death preparation, assessing their spiritual needs. We spend a lot of time educating the family and the caregivers about what to expect.* (Respondent 12)

CAREFUL, PLANNED TRANSITION AT END OF LIFE, IN COLLABORATION WITH PALLIATIVE CARE/HOSPICE

At the point that disease progressed and symptoms worsened, respondents emphasized the need for flexible and immediate response to avoid unwanted hospitalization and emergency dialysis. A key was proactively introducing the palliative care service BEFORE the crisis. Nephrology informants emphasized that they leaned on the palliative care or hospice service to organize the many details for orchestrating a comfortable death, particularly if the person wanted to stay at home.

LESSONS LEARNED ABOUT ADVANCING MEDICAL MANAGEMENT WITHOUT DIALYSIS

The dominant theme among informants was that dissemination of best practices and sharing of information in conservative management of ESRD has been problematic. Informants observed that, contrary to the perception that medical management without dialysis is [exclusively about managing] symptoms, it also includes educating patients and families about symptoms to anticipate as kidney disease progresses, then giving people tools to deal with them in a non-pharmacologic manner. Additionally, if patients choose medical treatment and advance care planning, conservative care involves discussing care goals, such as putting in place a crisis plan (e.g., when they go to the emergency department), ensuring that these plans are documented, accessible, and communicated, and that goal attainment is evaluated.

Informants also shared that integration of health information systems among healthcare facilities enables access to advance care plans when they are needed. Ensuring that medical management without dialysis is part of such health records is critical to the success of these programs.

Several informants cited close relationships with palliative hospice teams in the community as very important, such that mentors are identified and rapport is developed to facilitate collaboration in a “symbiotic relationship”. One informant (from Australia) strongly suggested that the failure of collaboration between palliative care specialists and nephrology, like other specialties, is attributable to the way palliative care is set up in the hospital setting. The argument was made that instead of having a separate palliative department, that palliative specialists be devolved (and attached) to various other specialties for on-demand, integrated consultation throughout the course of disease and not just at the end of life.

On success factors when initiating a conservative program, one informant advised that the best way to start is with patients who are resolutely decided about the non-dialysis path and use the experience working with them to learn. Clearly resolute patients remove the moral distress and the difficulty associated with it.

The importance of cultural context and competence in navigating advance care planning was highlighted, due to the observation that values and perceptions pertaining to meaning of life can vary across cultures. Finding evidence-based decision aids developed from rigorous research was also discussed. Decision aids that are systematically developed by mapping attributes and values that are important to most people or stakeholders help the advance care planning conversation be useful to patients and providers.

Informants also emphasized the importance of patient education about medical management without dialysis, along with related support and follow-up for patients who decide to pursue medical management without dialysis, arguing that good education reduces dialysis pathway recipients and also reduces reversions for conservative pathway subscribers.

Frailty was identified as a common occurrence for renal patients with multiple comorbidities, who tend to need good palliative care and good symptom control in hospice care. Home service was identified as a necessity for some of these patients, for whom it can be extremely difficult to go to the hospital or clinic.

NEED FOR KNOWLEDGE BUILDING IN SUPPORTIVE NEPHROLOGY

Informants identified a need to build palliative care knowledge in nephrology. One approach that was identified as a successful model was collaborative cross-team learning. One informant discussed how a collaborative project between nephrology and palliative care compared healthcare utilization among older adults with serious illness during the last six months, with the goal of highlighting the extent of need for palliative care services and how cost-effective well-organized outpatient palliative care services can be.

Informants conveyed that the general perception was that ESRD patients "…have very good deaths, relatively asymptomatic," and yet in reality they "…are pretty horrific, these deaths..." There is still a lack of knowledge about trajectory and causes of death for renal patients, how many withdraw from dialysis, and cost comparisons under different options of care. Informants decried the lack of inclusion of medical management without dialysis data in national databases and general health information architecture (e.g., EHRs), identifying this as the main information gap which limits the ability to sustain medical management without dialysis approaches as a choice, to plan for it based on prognosis, and to facilitate important analyses of medical management without dialysis outcomes. Furthermore, EHRs are currently not set up to measure outcomes of value to medical management without dialysis or palliative care. For instance, a challenge identified was that "treatment withdrawal" (e.g., dialysis withdrawal) cannot be coded in the medical record as a primary cause of death in some countries, and so there is no formal collection of data on dialysis withdrawals. Furthermore, most countries' renal registries do not track patients who opt not to have dialysis. This leads to alternative information collection mechanisms such as spreadsheets or a deductive investigation review of charts. Thus important information, such as how many people have had advance care planning, cannot be easily queried from systems.

One informant emphasized building in, at the outset, a way of collecting information to help evaluate performance and important outcomes. Example outcomes of interest include

- Advanced care planning initiation and completion
- Preferred place of death recorded and concordance with the actual place of death
- The dialysis quality of dying APGAR
- Bereavement follow-up of family members
- Percentage of deceased patients referred to hospice
- Percentage receiving palliative care
- Percentage of deaths in acute hospital or ICU
- Survival data
- Quality of life
- Time spent in hospital vs home doing treatment
- Family member involvement

The information gap also extends to a lack of solid understanding of interface between CKD programs with a strong medical management without dialysis component and dialysis programs. Informants communicated that filling this information gap would help illuminate the impact that patients coming in to start dialysis have on the overall cost of care and help demonstrate how effective implementation of medical management without dialysis (e.g., palliative care) on the front end helps reduce overall cost on the dialysis side. The interface would also enable access to the claims data for patients with CKD in this context and facilitate comparisons.

Some informants decried the reliance of prognostic predictions on group averages and indicated that prognosis would be more informative to individual cases when more individualized predictions can be done and customized treatment made possible at the individual level based on unique conditions.

Another major concern that informants conveyed was that decision tools for dialysis patients are very few, and the few ESRD tools that exist do not cover the conservative management treatment option.

THE PATIENT EXPERIENCE

Many respondents had been motivated to move toward integrating palliative care approaches into their practice because they had learned from the experiences of particular patients or groups of patients. Several informants had conducted and published formal research about the patient experience, both quantitative and qualitative. Other informants had not conducted formal research but had many observations to share from clinical experience. One theme discussed was encountering a patient who adamantly refused to start dialysis, often catalyzing the provider to re-examine how to support such a patient. Another theme was observing the unaddressed suffering of patients even when they opted for dialysis. A third theme was observing the trajectory of the patient's experience, whether on dialysis or not.

The observation of several informants was that most ESRD patients tend to be fairly stable for a while until they reach a sudden "cliff," after which symptoms deteriorate very rapidly before death. This makes putting advance care and crisis plans in place very important. Palliative care services also needed to learn how to work with renal patients before they exhibited severe symptoms. Initially, when patients were referred early, some palliative care services judged that the patient did not have any palliative care needs. The palliative care services needed to understand that they played a role in anticipating and planning for coming decline. Lack of planning and anticipation can lead to unavailable palliative care when it is needed, especially given how steep the decline to mortality can be for ESRD patients in the final days of life.

One informant discussed ways in which unwanted dialysis is prevented, citing documentation approaches for symptom management preferences rather than dialysis treatment. In Canada, the ambulance team entering the home of a patient in crisis will check on the refrigerator for documents, and if documentation of a non-dialysis pathway is found, they start palliative treatment and contact palliative teams to continue the treatment.

Informants also communicated that there is some psychological burden associated with knowing the grim prognosis of ESRD, so burdensome that it may contribute to accelerating mortality.

Informants discussed that the quality of life for dialysis patients can be very poor, such that the dialysis itself is just barely keeping them alive while they are bedridden and not participating in daily life activities. One informant added that in such cases, dialysis does not add any benefit to the patient.

An informant communicated that some families of deceased patients who withdrew from dialysis described the patients as being in a state of euphoria after deciding to withdraw and made arrangements to meet with family. That was then followed by a period of "waiting to die," which although in some cases was about five days, seemed very long for the patients. According to the literature, the median survival after dialysis withdrawal is about 10 days.

Respondents shared a conviction that both supportive care during dialysis and conservative management are effective strategies for improving the patient and family experience during a difficult and challenging time. One respondent asserted that their conservative management program helped family members cope with bereavement more successfully:

> *I think they're more prepared. We talk a lot about anticipatory grief and there's a lot of opportunities to help people leave a legacy. I feel like when people go through our program, there's not that abrupt end to things. This has been a journey, not so much an "all of the sudden it's over" kind of thing.* (Respondent 12)

DISCUSSION AND SUMMARY

LIMITATIONS

Respondents were drawn as a convenience sample and may not be representative of the views of the wider community of nephrology staff involved in delivering kidney supportive care. Views of nephrology team members, such as dialysis technicians and chaplains, were not included, nor were any primary care providers interviewed.

DISCUSSION

There was striking agreement as to the components needed to deliver kidney supportive care, including conservative management, even across the five different countries in which the respondents practiced. The common components included

- Appropriate patient identification
- Communication, advance care planning, and goals of care conversations
- Symptom assessment and management
- Collaboration with palliative care
- Early referral to community resources such as hospice

Despite this consistency in the components of care, there was variation in delivery methods. The specific models that had been adopted arose from local circumstances and coincidences, such as developing a collegial relationship between a nephrologist and a palliative care expert. Many respondents emphasized the need to measure the impact of their programs via outcomes, especially to make the case for more or continued funding. However, no one reported systematic efforts to understand best practices for implementing the care. For instance, some programs were built around capacity to deliver home-based services while others were solely clinic-based. There was also variation as to whether the services were nurse-led or physician-led, although all respondents valued an interdisciplinary approach. There was also variation in the way that specialty palliative care was integrated with the nephrology service, with some respondents strongly favoring embedding a palliative care specialist within the renal service and others using more of a referral approach. The amount of variation among services gives rich opportunity for future pragmatic research.

CASE HISTORIES

1. HOPE PROGRAM: HELPING OLDER PATIENTS WITH ESKC. A COMPREHENSIVE PROGRAM OFFERING ADVANCE CARE PLANNING, OPTIONS FOR MEDICAL MANAGEMENT WITHOUT DIALYSIS, AND SUPPORTIVE SYMPTOM MANAGEMENT WITH DIALYSIS. (AUSTRALIA)

Contributor:
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Kogarah, Sydney, New South Wales, Australia

Setting: Major metropolitan area renal unit.

Beginning history: Began in 2005, when nephrologist and palliative care specialist began to work together to address the suffering and struggling of patients on dialysis.

> Nephrologist: “I had a number of dialysis patients who were struggling, and I couldn't really put a finger on it. They just weren't well and weren't enjoying life; dialysis was a burden. And, I'd look at all of their chemistry and all the tests we were supposed to do and it all looked fine. At the end of the day, I thought we've got to be able to do something better than this. And, fortuitously, we have a very good palliative care specialist here. So, I spoke with him and said what could we do for these dialysis patients to try and make their lives better? He is just a very generous man, and as part of his existing role, without charging us, he just got involved to try and help us with symptom control for those patients and just the general holistic care approach. And, it seemed to make a difference. We didn't have proper trial of that, but it seemed to make a difference.”

The program began with symptom management and holistic care for dialysis patients in collaboration with specialty palliative care. They were able to collect enough data to convince the health department to provide pilot funding. They initiated the conservative care pathway after they had demonstrated improvement for dialysis patients. By 2012, they had sufficient positive results to get local funding from the hospital to maintain the program. Getting providers to accept the conservative care pathway was more challenging. There was skepticism because the heads of most renal units were “still quite opposed” to these innovations at the beginning. But, there were a few nephrologists who engaged.

At the same time, they began having all trainees who came through the program spend time in both the renal supportive care clinic as well as their usual renal, dialysis & transplant clinics and learn the symptom-based holistic approach. The nephrologist and palliative care physician gave many talks around the country about their program.

> Nephrologist: “And, around the country what we were finding was that wherever we would go the theaters would be packed with dialysis nurses. And, these talks would almost be like a cathartic bereavement session for the nurses because it was apparent that they were the ones who were really suffering watching the dialysis patients suffer, with no other program in place apart from the nephrologists walking in and walking out. So, that was the starting point. And, then by this time of course, what I've learned is if you've got the nurses on board, you've got a bigger chance of getting the doctors on board.”

Program model and services:

- Patients with advancing CKD attend a renal options clinic (used to be called a pre-dialysis clinic, but most units now are changing the terminology to renal options clinic). The option of a conservative non-dialytic pathway is presented along with dialysis and transplant options. Staff provide an information document to patients to take home and read that describes dialysis. “It's kind of a bit brutal in that it describes the survival on dialysis. Because that's often not put forward, and as part of informed consent we are actually obliged to provide that. And, then it describes what could happen to them on a non-dialytic pathway.” Then patients return for further discussions, and a decision about approach is made with the nephrologist.
- At the hospital, the team has a monthly meeting of all the nephrologists with the senior dialysis and supportive care nurses and transplant nurses. At this meeting, the team discusses any of the patients with GFR below 15 who are heading toward the end stage kidney disease pathway. And, if anyone is over 75, we have a mortality discussion about comorbidities, functional status, nutrition, etc. That is helpful because it allows the team to discern, “Okay you are over 75, but you're actually quite okay in many respects and dialysis is appropriate, or the converse.”
- Between 75% and 80% of the conservative management patients have an advance care plan, which is put on the alerts component of the electronic medical record. If the patient goes to the emergency room, the hospital emergency physicians will see that there is an alert, and the alert will be their advance care plan which will say "I'm not to have dialysis." Family members are key to having the patient’s wishes respected. “We've had numerous instances of that now where the family has kind of been empowered to tell the physician that they haven't met before that this is not an appropriate line of treatment for them.”
- Home visits are a key part of the pathway, particularly for frail elderly who may not be able to come in for a clinic visit. For these patients, there are two services. First, the renal supportive care nurse will do a home visit. Second, the renal supportive care team, generally the palliative care specialist, will make a phone call to the son or daughter, or partner, or whomever, of that person to see how they're doing and whether we need to be thinking about any other symptom changes and so forth.
- Once the patient gets to end of life, the community palliative care team becomes involved and assists with end-of-life management at home. That works quite well.

Results: About 25% of patients choose conservative care. To date, 300 patients have chosen the conservative care pathway. Of those, only three have changed their minds and gone on to dialysis at the last minute.

Spread: The approach has spread widely across the country, in part because trainees who were exposed to supportive care and conservative care have wanted to establish it in their areas. In 2015, the NSW health department provided funding to roll out the program to every renal unit in the state. The nurse-led model has a skilled nurse in each renal unit, with support of a nephrologist and palliative care specialist where possible. Most now also have some level of support from dieticians and social workers. There are three centers of excellence, called “hubs,” where nurses and doctors from all the renal units around the state can come to learn about the program and take those skills back to their own units. All renal units in the state now have both a conservative non-dialytic pathway program and a dialysis supportive care management program.

Next steps: Starting a cardio-renal clinic, which will involve supportive care, and have a physician running it who has nephrology, palliative care, and cardiology skills.

Pearls:

- A key to getting nephrologist support before establishing a conservative care pathway is to start by improving symptom control for patients on dialysis.
- Nurse engagement is critical.

Publications: (Brown et al., 2015)

Brown MA, Collett GK, Josland EA, Foote C, Li Q, Brennan FP. CKD in Elderly Patients Managed without Dialysis: Survival, Symptoms, and Quality of Life. *Clin J Am Soc Nephrol* . 2015;10(2):260-268. doi:10.2215/CJN.03330414.

Hoffman A, Tranter S, Josland E, Brennan F, Brown M. Renal supportive care in conservatively managed patients with advanced chronic kidney disease: A qualitative study of the experiences of patients and their carers/families [online]. *Ren Soc Australas J*. 2017;13(3):100-106.

Josland E, Brennan F, Anastasiou A, Brown MA. Developing and sustaining a renal supportive care service for people with end stage kidney disease. *Renal Society of Australasia Journal* 2012; 8(1): 12-18.

Brennan FP, Collett, Josland EA, Brown MA. Symptoms of patients with CKD managed without dialysis. *Progress in Palliative Care* 2015; 23:267-273.

Stevenson J, Meade A, Randall A, Manley K, Notaras S, Heaney S, Chan M, Smyth A, Josland E, Brennan F, Brown MA. Nutrition in Renal Supportive Care: Patient-driven and flexible. *Nephrology*, 2017. 22(10), 739-747.

Wainstein M, Menzies A, Brennan F, Brown MA. The legal doctrine of informed consent and renal dialysis - do patients really consent? *Journal of Law and Medicine*. 2018, 25:992-1008

Urban AK, Foote C, Brennan FP, Brown M, Lee B. Retrospective chart review to assess domains of quality of death (recognition of dying, appropriate limitations, symptom monitoring, anticipatory prescribing) of patients dying in the acute hospital under the care of a Nephrology service with RSC support over time. *Nephrology*. 2018; 10.1111/nep.13447

2. NETWORK OF CONSERVATIVE CARE PROGRAMS AND MULTIDISCIPLINARY CKD CLINICS (CANADA)

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Setting: Renal services for southern portion of province, including a major metropolitan area, several smaller cities, and rural areas. About 20 nephrologists care for about 1,000 end stage renal disease patients.

Beginning history: In 2006, nephrology called the palliative care team to consult with a nephrology patient in the hospital, and the palliative care doctor said "you guys really need our help." The problem was that patients who were on dialysis had a lot of decisional conflict. Patients were told "do dialysis or die," but when they went on dialysis, it didn't provide the quality of life or relief from symptoms they had expected.

> Nephrologist: "There was a lot of distress around mismatched expectations about what dialysis would provide. Poor symptom control, so lots of pain issues. A lot of distress around the dying process. If someone chose to withdraw from dialysis, it all happened in hospital and their symptoms weren't necessarily well managed toward the end. Just a lack of advance care planning and not really knowing what people's wishes were and then something catastrophic would happen and families being quite distressed when you're trying to figure out what their goals would be in a particular situation."

To help with the situation, the palliative care team began spending a lot more time assisting with the nephrology service. The nephrology service then decided to support one nephrologist who was two years out of nephrology residency to do specialist training in palliative care with the plan of coming back to build capacity in renal supportive care.

They began with building a conservative care program for patients who were clear that they didn't want dialysis.

> Nephrologist: "You want to start with the clearly decided [patients]. When you're starting a program, you don't just want to pick those really difficult cases that cause moral distress. You want the individual who has clearly decided 'I'm not going to do dialysis,' and they're very firm about it. Those are the individuals you want to make sure you support. In supporting those individuals, you develop the skills."

The conservative care program built upon province-wide efforts already underway to make a more robust advance care planning infrastructure. An existing system of multidisciplinary clinics caring for patients with eGFRs below 30 provided a clinical structure for the program.

Program model and services:

- The nephrology center had a pre-existing multidisciplinary CKD clinic and embedded the conservative care program (CCP) within it. The multidisciplinary clinic generally cares for patients prior to choosing dialysis or conservative care. Clinic patients participate in education about different treatment options. Individuals who go through that education and decide that they are not interested in dialysis and indicate that they'd be accepting of a palliative approach are then referred to the CCP program.

- The CCP cares for patients after opting to forgo dialysis or after withdrawal from dialysis if they are not actively dying. The CPP is staffed by a nephrologist with fellowship training in palliative medicine, an advance care planning nurse clinician, and a full-time dedicated conservative care nurse (position shared between two individuals). A social worker and dietitian are also available as needed. Census is usually about 50 patients.
- The CCP provides patient education about ESRD and about a trajectory without dialysis. Because patients choose enrollment into the program, the CCP provides active medical care that is specific to the goals and wishes of patients and their families. Symptom control is a priority.
- Criteria for acceptance into the CCP are a GFR less than 15, having received formalized education about treatment options and chosen conservative care, accepting a palliative approach, and then engaging in some discussion about goals of care.
- Patients are followed in clinic and between clinic visits with phone calls and home visits. Services are individualized to patient needs. The program also offers facilitated advance care planning, which includes a Goal of Care designation and bereavement follow-up with family members. Patients are encouraged to maintain relationships with their primary care providers.
- The key to the care is that “the nurse goes through and spends a lot of time figuring out what the individual's goals are and sorting out their wishes like where do they want their care to take place, do they want resuscitation, what are the important things? Do they have important events in their lives that they want to try and reach, like a wedding, or do they want to travel somewhere? Then she goes through and does an assessment of symptoms.” The nurse uses a checklist that includes medication rationalization and customizing lab tests so that they help support the patient’s goals. A lot of time is also spent on the logistical aspects related to planning for someone's death, such as where do they want their care to take place and how that would unfold. When individuals start to deteriorate, they are transitioned to hospice program.
- The nephrologist described proactive planning to be ready for escalating need, “To provide good end-of-life care we need to be able to ramp up end-of-life care really rapidly. It seems to be a cliff they go over. Everything has to be ready. We have to have all the forms filled out. We usually get the hospice team to meet them in advance and not necessarily do a lot of care, but they're in their system, they're registered. We use a resuscitation form that is kept on the refrigerator. If someone doesn’t want to go to the hospital, it very clearly indicates this. If 9-1-1 is called and the paramedics go out, the paramedics see this. They'll try and deliver care in their home, and they'll start palliative treatment and get the palliative care team out to see the patient rather than transferring them to hospital. In the event that they do go to hospital, we have a detailed letter that explains their wishes. We have both an electronic record and a folder called “the green sleeve” which holds their goal designation form. It also has a letter that explains what conservative care is, and it clearly says to give our program a call. When they see the high creatinine, they'll often call nephrology, and nephrology will say this patient is conservative. They often get admitted for palliative treatment, and they don't get started on dialysis.”

Results: Initial results for 154 patients enrolled in the CCP between 2009 and 2015 have been published. Mean age was 81 years and mean modified Charlson Comorbidity Index score was 3.4 ± 2.8. The median duration of conservative care participation was 11.5 months. Six (3.9%) patients changed their modality to dialysis. One hundred three (66.9%) patients died during the study period. Most patients who died (88.2%) completed at least some advance care planning before death, and most (81.7%) of them died at their preferred place. Twenty-seven (26.7%) individuals died in hospital.

S**pread:** It took three or four years for the program to mature. Now there's a maturity to communication about conservative care and it being a viable option. When a conservative care program exists, people talk about it like a legitimate option. Whereas, when you don't have it, people say things like “it's dialysis or death.”

Next steps: The service is now offering palliative care to individuals treated with dialysis tailored to individual patient goals. The next step is improving supportive care to the dialysis patients by implementing some of the things that proved successful in the CCP. For dialysis patients, they are identifying high-need patients using a multivariable prognostic model that includes the Surprise Question[1]. These patients are offered facilitated advance care planning and palliative care consultation.

Pearls:

> “I thought it would be a lot of symptoms, but it hasn't been. It's really been a lot of advanced care planning and care planning and a lot of discussions about goals and trying to figure out what people want and ensuring that their care is in line with those goals… A big part of what happens is really reviewing goals and choices, making sure that they're resuscitation status is documented and the appropriate forms are filled out, making sure that there's a crisis plan in place and that there's time to do death preparation, assessing their spiritual needs. We spend a lot of time educating the family and the caregivers about what to expect.
>
> Bereavement for family members of patients in the CCP is different. I think they're more prepared. We talk a lot about anticipatory grief, and there are a lot of opportunities to help people leave a legacy.
>
> One of the keys to success is having a really good relationship with the hospice team who can help you learn skills and can help your patients transition. If you don't have that, I don't think any nephrology program has the capability to take that on. You really need to partner and teach them and have them teach you. Without that, I don't think you can have a successful program.
>
> You need a strategy for when people do go to the emergency department or the hospital and a way of communicating and making sure that the person's wishes are known and the team at the hospital knows what's taken place in advance of getting there.”

Publications:

Kamar FB, Tam-Tham H, Thomas C. A Description of Advanced Chronic Kidney Disease Patients in a Major Urban Center Receiving Conservative Care. *Can J kidney Heal Dis*. 2017;4:2054358117718538. doi:10.1177/2054358117718538.

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[1] The surprise question (SQ) was developed more than a decade ago and has been suggested as a simple test to identify patients who might benefit from hospice and palliative care (HPC). It involves a clinician reflecting on the question, “Would I be surprised if this patient died in the next 12 months?”. It was thought that the SQ would correct for a physician’s tendency to overestimate prognosis by asking the physician to consider whether death in the coming year is possible rather than probable. The surprise question has been widely promoted and adopted into frameworks for assessing hospice and palliative care needs. [6]

3. “RENAL ELDERLY CARE NURSE” ROLE (GREAT BRITAIN)

Contributor:
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Setting: Large metropolitan area peritoneal dialysis program and an associated hemodialysis center.

Beginning history: Over several years, the nephrologist leading the peritoneal dialysis program had successfully integrated advance care planning discussions into her own care of patients, but found that colleagues were resistant to such discussions. Many of the senior clinicians refused to talk about end of life or resuscitation and were committed to a philosophy of extensive dialytic treatment. Although many centers in the country had a role for a supportive care nurse, these nurses were mainly working with patients choosing conservative care or with dialysis patients just at the last few days of life. She decided to work on integrating geriatric approaches into the renal care so that they could offer more proactive approaches to frailty and quality of life issues. They started with an 18-month grant to train a senior renal nurse in geriatric assessment skills.

> **Nephrologist:** “The thing that bothers me about just focusing on supportive care and conservative care is that you're just focusing on the dying. You're not actually trying to improve things. Focusing on frailty by thinking about it as a geriatrician actually tries to improve things.”

Program model and services:

- A full time senior nurse with extensive renal background spent two months training with local geriatricians and palliative care/hospice teams. She worked with the geriatricians on geriatric assessment and spent time in the dementia clinic, several weeks with the palliative care team, and a week in a hospice. This gave her expanded networks for making referrals. She also created her own modified geriatric assessment.
- Initially, the nurse screened everyone over the age of 70 and anyone over 60 who the local nurses deemed frail. She also screened everyone receiving peritoneal dialysis and patients at one hemodialysis unit.
- Screening identified large numbers of unrecognized needs including cognitive impairment, frailty, and falls. Moderate to severe distress was found in a quarter of the patients. Patients were referred for physical therapy, community services, falls clinic, memory clinic, social services, and palliative care.

Results: An evaluation of the impact of the geriatric nurse role with the first 90 patients showed an increase in patient satisfaction, decrease in distress thermometer scores, positive impact on workload of dialysis nurses, and reduction in hospitalizations.

S**pread:** The role of the “renal elderly care nurse” has been formalized, and three additional nurses have been hired in that role.

Next steps: Continue to follow patients receiving the renal elderly care to assess longer term impacts on hospitalization, dialysis and conservative care selection, and end-of-life experience.

Pearls:

- “This approach has gone down much better with my colleagues because it's actually trying to do something for them.”

Publications:

Abdulla A, Wright PN, Ross LE, et al. Proceedings From the Symposium on Kidney Disease in Older People: Royal Society of Medicine, London, January 19, 2017. *Gerontol Geriatr Med*. 2017;3:2333721417736858. doi:10.1177/2333721417736858.

CASE HISTORY #4

INTENSIVE SIMULATION-BASED COMMUNICATION TRAINING FOR NEPHROLOGY CASE MANAGERS (UNITED STATES)

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President/CEO
Alive Hospice
Nashville, TN

Setting
An urban hospice/palliative care program participating in an ESCO model

Beginning History
The hospice leader and the leader of the dialysis corporation were discussing the hospice becoming a partner in the ESCO. The dialysis corporation leader was describing their staff education program and onboarding.

> **Hospice leader:** (referring to dialysis corporation leader) “He was telling me all about their program and their education and their onboarding and some exciting things they've got in different markets and really so progressive and so committed to continuing to improve the space. After he went through all of that, I just looked at him and I said, ‘Tell me how you do the end of life because all of your patients die.’ He just went from total full smile. He physically almost crumbled. He said, ‘We're awful at it.’ I said, ‘Let's talk about it because that's what we excel at.’ That is the relationship and how it began.”

Program Model and Services
The hospice provides communication training to health professionals and students in a simulated setting that offers an opportunity to videotape practice sessions and receive feedback from the hospice faculty. Sessions are typically two hours. The dialysis corporation has enrolled all of its clinical care coordinators in this training.

More Information
Website: https://www.alivehospice.org/healthcare-providers/simulation-lab-1
News article: https://search-proquest-com.proxygw.wrlc.org/docview/1913588005/fulltext/2678B7E7081C44CBPQ/1?accountid=11243

TABLE 1: CHARACTERISTICS OF INTERVIEW RESPONDENTS

	Characteristic	**# of Respondents**
Country		
	Australia	1
	Canada	3
	Netherlands	1
	United Kingdom	7
	USA	5
Profession*		
	MD	12
	RN or advanced practice RN	3
	Psychologist	1
	Social worker	1
	Administrator (MBA)	
Specialty**		
	Nephrology	12
	Palliative care	5
	Other	1

*One person counted twice – nurse and as administrator
**One person counted twice – nephrology and palliative care

TABLE 2: SUCCESS FACTORS

THEME	**COMMENT**
PROVIDER TRAINING, ESPECIALLY IN COMMUNICATION	• Developed training both in symptom management and in advanced communication skills. Developed skills training called REACT (Renal Advanced Communication skills Training.) (Respondent 1) • Four module workshops for staff covering conservative management, advance care planning, nursing perspective, palliative care (Respondent 15) • Developed a master class which is to be run for any doctor that wants to come but particularly for the trainees in renal medicine and palliative care. Run a 1- to 2-day program once a year. Attempting to rotate latter around different states in the country. Have run [three] and we are hoping to run another. (Respondent 13) • “We have a conservative care nurse, and she's an RN. She's not an advanced practice nurse, but she's done lots of courses on communication and palliative care.” (Respondent 12) • “The most important thing that we do is… for a CKD care coordinator who starts in one of our programs to go down to (city of established CKD program) and spend three days and see what S. and her team does.” (Respondent 11)

	• "The education…has been probably the single biggest intervention that we've done… to be able to help give tools to folks to be able to begin to have comfort in these communications.... We have built a formal simulation lab for end-of-life conversations, and it's a pretty intense process that we take people through. It is for practicing clinicians. We've got a group program, and we've got an individual program." (Respondent 2) • "Training for fellows too is a big one because there's really no focus on communication skills. Observing fellows with patients and just doing some real communication skill training, as well as teaching all the stuff about symptom assessment and how to manage symptoms, and how to manage somebody medically without dialysis. For me that's a huge chunk of getting the next group more comfortable and ready to go on these issues." (Respondent 17) • "And what we had already started to do was that any trainee, nephrology trainee, coming through our unit would spend time in the renal supportive care clinics so that they got to understand what this program was all about. They would see the ancillary symptom-based holistic approach to the dialysis patient, and they would see the same thing for the conservative non-dialysis pathway patients." (Respondent 15)
PALLIATIVE CARE/ NEPHROLOGY COLLABORATION	• "The language is different, and I firmly believe that our palliative care colleagues, they just, I don't know, they're just raised differently. Even the docs, it's like people talk to people in a way that there's no agenda. Whereas the rest of us it's more like 'Okay, we've got to get this done. The DNR we've got to ...' That kind of attitude. Whereas I feel like our palliative care colleagues are much more 'Well, you know, we could do this or we could do that.' I mean it's like a different delivery, so I think it is what they bring to the table. (Respondent 17) • "I had about four or five other patients who said exactly the same thing – 'thanks but no thanks.' I thought, 'Gosh, what am I going to do with these patients?' They were under our care, but I knew very little about palliative care. I hadn't done any palliative care nursing, so I decided that I would book myself onto a palliative care course in the hospital. I decided that I would go and meet the palliative care consultant…at the end of it we agreed to develop a combined nephrology and palliative care clinic to improve patient care and learn from each other." (Respondent 3) • "I personally would prefer the input of expert palliative care. My experience has told me that I would prefer being able to export to palliative care physicians rather than trying to skill up myself. The different problems I encounter more are that the patient can't walk upstairs anymore to use the toilet. And, I don't know who to phone to get the downstairs toilet or commode organized for the patient. Whereas the palliative care physician does. They know their way around the care system." (Respondent 8) • "I think the close relationship with the hospice team in the community has been so important. One of the nurses out in the community has been an amazing mentor. She's a real role model, and she's taken a lot of nurses under her wing to mentor them and provide support. I think the success of our program is because of our relationship with this palliative hospice team out in the community. They know us. We invite them to our education sessions. There's a real back and forth. They've learned a lot from us. We've learned a lot from them. It's a really symbiotic relationship." (Respondent 12)

	- “We actually ran conferences or workshops where we got the nephrology and palliative care people to sit together in locality areas by table and talk to each other. And, it was fascinating because it was the first time some of them had met, and do you know, they ended up having conversations like, ‘Oh, can I come and see your hospice? Can I come and see your inpatient palliative unit? Can I come and see your dialysis unit?’ And, so there was this flow back and forth that went on organically, where people suddenly started to go to a dialysis unit and learn what it was people had to go through. And what were the concerns that the dialysis staff were looking out for. And similarly, what was a hospice like, and why could they manage dialysis there, or whatever. And it's just been fascinating because it has meant there's sort of demystification of what the other side is doing.” (Respondent 1) - It was 2005 and what occurred to me was that I had a number of dialysis patients who were struggling and I couldn't really put a finger on it, they just weren't well and weren't enjoying life; dialysis was a burden. And I'd look at all of their chemistry and all the tests we were supposed to do and it all looked fine. At the end of the day I thought we've got to be able to do something better than this. And fortuitously we have a very good palliative care specialist here in Dr. X and I had known him on and off over the years. So, I spoke with him and said what could we do for these dialysis patients to try and make their lives better? He is just a very generous man and as part of his existing role, without charging us he just got involved to try and help us with symptom control for those patients and just the general holistic care approach. And it seemed to make a difference. (Respondent 13) - The second part of the answer is I actually think palliative care has got it all wrong…We have palliative care departments. My view is that palliative care specialists should be embedded in other departments. We've now achieved that. I've got Dr. X, our palliative care specialist, he works solely in our renal department, nowhere else. He’s funded completely through our renal department. But, the notion now of just having a palliative care department is really not working because they're still focused on end-of-life. So I think that's been another reason it's taken so long for disciplines like nephrology, respiratory and neurology to really engage with palliative care. (Respondent 13)
CHAMPIONS (OFTEN NURSES)	- “The other thing that made a difference was the nursing staff who had really been under the pump because they could see all this, their patients not doing well, you know three times a week…. What I've learned is if you've got the nurses on board, you've got a bigger chance of getting the doctors on board.” (Respondent 15) - “I worked with a fantastic nephrologist, who everybody really respected, and he was very much on board, he was very patient-focused…. At the start, having him on board really helped, because his influence on his colleagues was crucial to change culture.” (Respondent 3)
MESSAGE/ COMMUNICATION ABOUT CONSERVATIVE CARE	- “There's a maturity about how you talk about conservative care and it being a viable option. When you've got a conservative care program, people talk about it like a legitimate option. Whereas, when you don't have it, people say things like ‘it's dialysis or death.’ I don't think you'd ever hear that in our program because people talk about it maturely, and I think just that open discussion has been helpful.” (Respondent 12)
CULTURE CHANGE IN NEPHROLOGY	- “Okay, you need these dedicated professionals to lead the service, but actually you need to change the culture within the whole of the renal unit. In the

	beginning there were nephrology colleagues that were not so on board with palliative care and conservative management (no dialysis)…" (Respondent 3) • From all of that experience, I think that first, things were shining on the nephrologists that their dialysis patients benefit from this approach, before trying to get them on board about the conservative non-dialysis pathway and secondly, having the nurses engaged in this approach is a primary issue. I think they would be two key learning points to be used. (Respondent 15)
RESEARCH DATA, ESPECIALLY SHOWING IMPACT IN LOCAL SYSTEM	• "I think here in the hospital it's really accepted, and I think the research we did here helped also establish it and convince even more, for example, renal nurses." (Respondent 16) • "We've had pilot studies, the data showed that the patient's families are quite satisfied with this program." (Respondent 15) • "With the mentorship of a palliative care colleague I collected data on patients managed conservatively without dialysis, and we began to publish papers. At the time there was little evidence to guide practice in this area." (Respondent 3)
NATIONAL GUIDELINES	• "What is helping is there is a recent national guideline on decision making on renal therapy, and they have really used our data and also, of course, international data and they have a very state of the art how-to approach on this." (Respondent 16)

TABLE 3: BARRIERS AND CHALLENGES

THEME	**COMMENT**
ATTITUDES, KNOWLEDGE DEFICIT, CULTURE	• “I think it's not just the tools, it's the staff who are doing things because if everybody's attitude is "If they don't do dialysis they'll be dead in a couple of weeks," then it kind of doesn't matter what video you have, because the clinicians are, they have their pitch that is always going to be biased to whatever they think.” (Respondent 17) • “I worked clinically but also had a project management component to my role, to develop a palliative and end of life care service. The aim was to embed palliative care within the renal unit, but actually we didn't even scratch the surface after three years. There were some nephrologists who were still very resistant to change, in terms of introducing palliative care into dialysis and nephrology generally. So that was quite a challenge, really.” (Respondent 3) • “Honestly, I think that one of the main barriers is just trying to get more education to the nephrologists, nurses, all staff because I find a lot of people aren't comfortable talking about it. I think that's the big barrier.” (Respondent 15) • “There is a large number of physicians who don't know anything about [conservative care]. I still experience that during talks or during whatever meetings, but I experience, ‘Oh, can you really not start dialysis?’ And, they ask me the same questions I was experiencing before doing this research. I thought patients who decided to not start dialysis would die in about a few weeks and months. That was also a bit my feeling, but I was really proven wrong. While this is also very surprising still for many doctors. There is large knowledge gap I think, still.” (Respondent 16) • “I said, ‘How many of you feel like you're dialyzing dead in your clinic?’ I would say a significant portion of them raised their hands. I said, ‘That's the reason I'm here. Because if you know that burden is outweighing benefit, have you communicated that to your patients and their families?’ We have a responsibility as human beings in order to be able to have that level of honesty. (Respondent 2) • “Then we got a few [nephrologists] whom I call the highly unengaged. There are about three or four of them who are not on board with the philosophy of conservative care or palliative care. The rest of the program pretty much everyone else is on board, and if a patient expresses that they don't want dialysis, then they'll support them.” (Respondent 12) • “For one of the consultants I spoke to, he said ‘I never speak to people about supportive and palliative care because I don't see that as an option. I will always try. I will always offer something.’ There's this feeling that if you offer supportive and palliative care, you're stopping treatment. So that's a problem.” (Respondent 4) • “And, the thing that bothers me about just focusing on supportive care and conservative care is that you're just focusing on the dying. You're not actually trying to improve things. And, focusing on frailty by thinking about it as a geriatrician, actually tries to improve things. Not just the symptom control.” (Respondent 9) • “As a nephrologist I thought I was doing it… and still take pride in thinking that I'm taking a holistic approach to my patients and so forth. And, I have to be honest, it was only when we really got stuck into this program (renal supportive care) did I realize how many symptoms I was missing. The patients, they don't want to bother me with it because they can see I'm busy, running a busy clinic, and you know I ask them, ‘How are you doing?’ and they'll say just ‘I'm fine.’ And symptoms? ‘No, I'm, good.’ Whereas that same patient when they're filling out the IPOS symptom survey in the waiting room before the renal supportive care clinic, they might have seven or eight symptoms.” (Respondent 13)

TABLE 3: BARRIERS AND CHALLENGES

THEME	COMMENT
	• "So the support care register reduces that [unwanted dialysis on emergency basis for emergent hospitalization], but yeah, it still can happen that a keen young resident maybe lacks the confidence to keep someone comfortable rather than to make them better with a machine." (Respondent 6)
DIALYSIS-CENTRIC APPROACH	• "We do have a clinic for people with advanced CKD, but it's called a 'pre-dialysis clinic' so that kind of gives you a hint of kind of how everything was approached in this clinic." (Respondent 17)
ECONOMIC INCENTIVES	• "Yes, I think it's particularly hard for nephrology because the money is made in dialysis, not in clinic. The leadership has to really make a conscious decision to redistribute money, whereas they tend to just look at the bottom line. Money is made by putting people on dialysis. Money is made when the surgeons put in a graft or a fistula, or the radiologists get money when they de-clot the thing, not when we sit in clinic and have long deep conversations about what are you trying to leave the world." (Respondent 17) • "Since that's the primary source in some way or another of our referrals, if we don't have an arrangement, either a clinical relationship or a financial incentivized tie like an ESCO with a nephrologist, it's really hard to get the nephrologist to engage." (Respondent 10, from perspective of a palliative care service) • Basically what we did is identify why isn't outpatient palliative care happening at scale; the answer was clearly there was no reimbursement model for it on a national basis. So we started saying, 'Who could reimburse for it?' And, the answer was payers. So, Medicare Advantage being a potential core customer, but also commercial Medicaid as well, some regular commercial insurers, albeit a smaller percentage of the population. Then you look at ACOs. So, the challenge of ACOs, we pretty quickly learned, is not that the economics didn't work at the end stage, but at the beginning stage." (Respondent 10) • "Because if you know that burden is outweighing benefit, have you communicated that to your patients and their families? We have a responsibility as human beings in order to be able to have that level of honesty. That's a tough place to be for dialysis companies because, I don't know your world but, dialysis companies, from my understanding, don't get paid if they don't dialyze. So it's a perverse financial incentive oftentimes." (Respondent 2) • "The financial incentives drive so much, and we have perverse and mal-aligned financial incentives in healthcare. So there is a concern that if you keep certain people from going on having dialysis and becoming part of the ESCO, then you're changing the underlying financial platform or the work model in your ESCO which then creates an appearance of better or worse savings than you otherwise would have had. So it all comes back to the dollars as opposed to continuing to be able to be focused on what are the right human things to do." (Respondent 2) • "Obviously we don't have the same system as you, because we've got one provider for everybody, almost everybody. And most of the funding is a sort of purchaser-provider split, so there's an artificial distinction between who provides a service and who pays for a service. And, actually it all comes down to the same person in the end, because it's the NHS. So we don't have the same degree of issues that you have with for-profit providers." (Respondent 1)

TABLE 3: BARRIERS AND CHALLENGES

THEME	COMMENT
	• "There is a set flow of funding per dialysis patient. So basically if I go to the trust, the body that's running the acute hospital and the dialysis unit, one has to make a very strong case to justify doing something which doesn't have funding attached to it. So the director of the kidney unit had to make a business case as to why the service for renal supportive care should be supported. And, the business case was made very well, but it wasn't made on the basis of bringing money in per conservatively-managed patient; it was made on the basis of reducing bed days…freeing up those beds to be used for other people who did bring in income." (Respondent 1) • "One of our problems is that we don't have a mechanism for reimbursement in relation to conservative management. So we do for dialysis, but we don't for conservative management." (Respondent 1)
LACK OF EVIDENCE	• "Because one of the problems was we didn't have a whole lot of solid data; we had a little bit of data." (Respondent 13) • "And, so I went away to look and see what audit standards we could put in place to see whether we were reaching them, and I basically found that there was no evidence." (Respondent 1) • "There was nothing kind of set in stone as to how it would happen.… When we went to the literature, there was nothing about these patients anyway. So we had nothing to guide us. So it was back in 2007, I published a paper on renal supportive care." (Respondent 4) • "Because there was not enough data to say 'you will live this long' or what the prognosis comparison was. (Respondent 3) • "So I thought, 'Gosh, how am I going to study this population if I can't even classify it?' I realized was arbitrary as to whether or not a renal unit reported causes of death to the UK Renal Registry, and equally if they did, what did they understand as treatment withdrawal? How did they define it?" (Respondent 3) • Regarding U.K. Renal Registry: "The UK renal units under report cause of death data for dialysis patients to the UK Renal Registry, and we don't fully understand why this is. Nevertheless this means we don't have robust data about what dialysis patients die from or numbers of patients discontinuing dialysis prior to death. In addition, the lack of qualitative evidence means we know little about the decision making and experience of dialysis patients and their families at the end of life..." (Respondent 3) • "You don't want it to be a financial decision at all. It has to be the patient's own decision. But, if we can get people to make informed decisions and not to be commencing a treatment that is likely to do harm, that's where we're...we're stuck there. We don't know when it's going to cause harm. We aren't able to select the patient group that it's going to cause harm to." (Respondent 4)
LACK OF CONSENSUS ABOUT BEST PRACTICE	• "It's always been something that we've been trying to work on, but it's been a struggle.… What we're trying to work on is trying to figure out how do we talk to dialysis patients about advanced care planning. Specifically, when is it appropriate—when they're on dialysis, when they're not on dialysis? How do we get the family there? How do we have the time? As I'm sure you're aware, it's very limited." (Respondent 15)

TABLE 3: BARRIERS AND CHALLENGES

THEME	COMMENT
LACK OF COORDINATION WITH PC OR LACK OF PC CAPACITY	• "What we did, which I think we could have improved on, is we worked a bit in a silo. So we didn't really work very closely with the palliative care physicians." (Respondent 4) • "Definitely getting support, the palliative care support. That was a challenge initially, and we're happy that's been improving." (Respondent 15) • "The other thing we had a big worry about, or at least I didn't, but some of the others did, was if we start to assess symptoms and problems in this population, will we suddenly open the floodgates so that the palliative and hospice services get overwhelmed?" (Respondent 1) • "Concerning late referral to palliative care/hospice: I think there's this reluctance to refer because they don't want their patients stuck in this.... There's been some decision making that's happened, and I would argue it's not necessarily informed decision making. Some of these patients—maybe peritoneal dialysis may have been an option for them. Somebody's made a decision that they're not for dialysis. They don't refer them, but they don't know what the journey for someone with death from end stage kidney disease without dialysis looks like. Then the person gets into crisis, and there's no plan in place. A lot of stuff needs to be in place for someone to die at home. It's not like you just go to sleep and don't wake up. Educating families not to call 911. You have to have the proper forms done. I think that they're just concerned about these people getting started on dialysis so they don't refer them." (Respondent 12)
LEVEL OF EFFORT/TIME	• "In the nephrology department, it's just no one has the time. We really have to spend time talking to people. When I talk to people in clinic about conservative management and the decision, just one family can take half an hour and then I'm behind." (Respondent 15)
LACK OF RESOURCES	• "We developed a home service as well because we started to realize that some of these patients found it very difficult to come to the hospital. But, that has been very difficult to continue, and I think at the [hospital] now, they don't offer a home service anymore because they now have a hundred patients whom they manage within that service. It's nurse-led, there are two nurses, and they have advanced nursing skills so they do prescribe and they do do nursing assessments." (Respondent 4) • "It's the type of service that is always going to be a little bit threatened… In things like palliative care, supportive care, it's easy to pull away staff from those sorts of services. If you've got patients coming in to dialysis, you have to have staff working in there, so there's always a little bit of a threat." (Respondent 4)
REGULATORY ISSUES	• "The hospice regulations still prevent.… The only simultaneous dialysis hospice patients that we have are those, and it's very few, who have a terminal diagnosis but separate from the ESRD." (Respondent 2)
PATIENT CONCERNS/ BROADER CULTURE	• "It's more than just understanding medical care and medical futility and appropriate utilization of care and education. There's a whole complicated factor of the cultural component that has to be addressed and cannot be dismissed. I think it's nationally and internationally, but I will say honestly for sure in the South (of United States)." (Respondent 2) • "This was a bit of the barriers, which was solved this way: to make very clear and reassure that the nephrologist remains your nephrologist and you are allowed to be seen here in the hospital. You aren't referred back to the primary physician." (Respondent 16)

TABLE 3: BARRIERS AND CHALLENGES

THEME	COMMENT
	• "So there's an awful lot of resistance, and we do have to go so carefully. This is quite a Catholic country as well. You don't want to have debates about death and dying. You just want to try and keep it very patient-centered, I suppose." (Respondent 4) • "There's also a real problem around what people understand about supportive and palliative care generally in the wider population. We are very death-denying, we don't talk about death, and it's felt, very much like around Sarah Davidson's work, that if you talk about death you're reducing hope. But, we know that particularly people on dialysis do want to talk, because no one talks to them and they're scared. And, they feel very lonely." (Respondent 4)

TABLE 4: MODELS FOR ORGANIZING KIDNEY SUPPORTIVE CARE AND/OR CONSERVATIVE CARE PATHWAY

CARE MODEL	KEY ELEMENTS OF CARE MODEL
THE "PREPARE FOR RESPONSIVE MANAGEMENT" PATHWAY (ENGLAND) Conservative care arm (called "responsive management") of Prepare for Kidney Care, a randomized controlled trial of preparing for kidney dialysis versus preparing for responsive management in advanced kidney disease in England. A detailed protocol describing expected service delivery at each visit is available: https://njl-admin.nihr.ac.uk/document/download/2011135	Prepare for Responsive Management pathway is one arm of a randomized clinical trial being conducted at multiple community nephrology sites in England. The Responsive Management pathway is a phased, individualized package integrating primary and secondary care delivered at home by a care coordinator. The model is based on the Kidney Disease Improving Global Outcomes (KDIGO) Consensus statement and in collaboration with experts and patients. There are three stages: 1. Assess: initial telephone call, followed by home visit(s) to conduct assessment and develop plan of care. In the first home visit, a comprehensive advanced CKD care assessment will be carried out and documented. This will cover: • Completion of iPOS-S renal • Symptom control and management • Continuity and co-ordination of care, access to services • Psychosocial needs • Information/communication needs • Advance care planning • Assessment of caregiver The first visit will generate an agreed personalized problem list and action plan including agreement of plan for next visit/contact. Two additional visits within 6 weeks may be scheduled as needed to continue assessment and care planning. 2. Responsive Management: During the responsive management phase, the patient receives monthly phone contacts. The patient continues to visit their nephrology clinic and assigned nephrologist at regular intervals. Home visits by the responsive management team replace every other clinic visit. The monthly phone contact consists of: • the health professional will compare current responses with previous responses looking for any worsening of symptoms and if present: • Review symptoms and treatment with the MDT and make any possible changes to medication to control symptoms • If clinically appropriate, arrange face-to-face contact either through a home visit or a clinic visit or a community team visit

	During this phase the patient continues to visit in clinic with their named consultant. The content of these clinic visits will be determined by the treating nephrologist but should not include preparation for dialysis unless the patient decides to withdraw from the responsive management pathway. If despite optimization of their medication the patient's symptoms are proving difficult to adequately control and the patient still wishes to follow a conservative care pathway, treatment will escalate to "Supportive care" . 3. Supportive care: If the patient develops symptoms of advanced CKD that cannot be adequately controlled, they progress to the supportive care enhancement stage. The advance care plan and any other documentation relating to priorities for care must be reviewed and the appropriate local community and palliative care services activated and coordinated to achieve good end-of-life care. This must be done rapidly to prevent inappropriate default "cure-centered" care being administered in the event of a sudden deterioration. In principle, the package of care should aim to deliver the following five patient priorities for quality end-of-life care (44): • Receiving adequate pain and symptom management • Avoiding inappropriate prolongation of dying • Achieving a sense of control • Relieving burden on loved ones • Strengthening relationships with loved ones Although the renal unit team may want to continue to lead at this stage of care, it is often more appropriate to hand over day-to-day management to the local community teams – palliative care and general practice. If earlier stages of the conservative care package have worked effectively, these services will already be aware of the patient and the possibility that they may need end-of-life support. Written and telephone guidance on prescribing in advanced CKD is generally welcomed by these teams, who may be unfamiliar with the appropriate drugs and doses to use in end-stage kidney disease
Renal Supportive Care, Australia Report from Renal Supportive Care Working Group (RSCWG) of the New South Wales Agency for Clinical	Renal Supportive Care (RSC) has emerged as a formal approach to addressing the gaps in care for patients with CKD being treated conservatively, and for those receiving renal replacement therapies but experiencing persistent symptoms. To facilitate the establishment of RSC services each renal unit in New South Wales was allocated to one of three hubs (St. George Hospital, Nepean Hospital, and John Hunter Hospital). The hubs provide education, mentoring, and

Evaluation.(Agency for Clinical Innovation (ACI) Renal Supportive Care Working Group (RSCWG), 2018) https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0020/443072/Renal-Supportive-Care-Service-Model.pdf(Renal, Care, & Committee, 2016) Additional information provided by expert panel contributor.	ongoing support to the units within their network. Renal units have been funded to employ nursing and allied health staff to support this program. A database was distributed to all units to ensure a standardized framework to collect data for the State-wide RSC Key Performance Indicators. **Key features of the NSW RSC model** The most important features of the NSW RSC model are that: • It is a **nurse-led model**. A Clinical Nurse Consultant (CNC) or equivalent occupies the central role in delivering RSC. The nurse is supported by a palliative care physician (or other medical/ nursing practitioner who can assist with the medical aspects of managing the high symptom burden of the target population) and a dietitian and social worker where available. The CNC is skilled in palliative care principles of care delivery, including attention to the physical, emotional, and spiritual dimensions of the patient's illness and care of the patient's family/caregiver. This is in addition to the nurse's knowledge and experience with CKD and end stage kidney disease (ESKD) and technical aspects of renal replacement therapies. • It is explicitly **embedded within existing renal services** and not as an adjunct to these services. The rationale for this is that RSC is most needed at times of high patient, staff, and caregiver stress, when transition to a new team is least likely to be successful. This also incorporates the principle of non-abandonment. That is, patients with CKD and ESKD will continue to receive care from their nephrologist and the renal unit, regardless of their decision to not embark on or cease renal replacement therapy. • A **nephrologist provides local leadership** for the RSC service. A nephrologist (already employed within each renal service) acts as the Director of RSC in that unit. The nephrologist provides clinical leadership for the RSC service, and oversees the implementation and governance of the local RSC program. • It is a **networked model**. A networked model is required to meet training and ongoing mentoring needs of RSC staff, and developing resources that can be shared. The model is based around the establishment of three "hubs" across the state selected for geographic convenience and existing expertise. These hubs are affiliated with specific renal services, providing education and mentoring to the staff of these services who then provide care for their patients locally. Patients do not need to travel to these hubs for RSC treatment. The hubs will also have an important role in research to improve the RSC model of care over time, and to compile data for accountability of services and evaluation of the effectiveness of the model.

	The cooperation that has developed between the renal service and the palliative care service, with access to a palliative care consultant who now spends time within the renal unit, has been fundamental to its success. The palliative care consultant works with the nephrologists to support the care of their patients, whether they are on dialysis, pre-dialysis, or conservatively managed. The renal supportive care service incorporates outpatient clinics, inpatient care, and the development of renal supportive care guidelines such as renal appropriate symptom management (using medications where appropriate that are suitable in ESKD), and providing ongoing education to staff and others. Outpatient clinics are run weekly but are limited by clinic space. Outpatient clinics involve not only patient consultations, but assessing symptom burden, referrals to allied health and community organizations, coordinating urgent admissions, and providing educational opportunities of other health professionals including trainees in renal medicine. Inpatient services include managing new referrals of ESKD patients from nephrologists for symptom management, participation in family conferences, end-of-life care (palliative care and supportive care share this role), appropriate referrals to palliative care institutions (hospice), expert symptom management advice for staff caring for renal patients (especially if the patient is not admitted to a renal ward or is admitted under another specialty for another reason), and appropriate referrals to other specialties such as to the pain team. The clinical nurse consultant (CNC) visits inpatients regularly to monitor progress when there has been a change in symptom management medications, to monitor pain and to support the patient and their relatives.
Canadian suburban nephrology practice with supportive care (Toronto suburb) Comprehensive Conservative Renal Care (CCRC) Pathway	Context is a suburban/urban nephrology practice with eight nephrologists who began implementing supportive care following Chandra Thomas' model about 3 years ago. To start the program, they first identified a team including a CKD social worker, two CKD nurses who were interested in conservative care, and a nephrologist who participated in training. Patients referred to the CCRC pathway are patients in the CKD clinic with a GFR of less than 15 who have decided not to have dialysis. Any nephrologist can refer to the pathway. Predominately, the primary nephrologist follows and the primary nurse follows. The CKD clinic has six nurses and they keep their patients. Once a patient is identified as CCRC they get an identifying sticker on their chart. The IPOS-Renal Assessment Form is used. At every visit, the patient meets with a social worker and they're encouraged to bring family.

	First visit: meet with a social worker to confirm their wishes. Once they've decided on conservative care, then they meet with the primary nurse who helps with the IPOS assessment tool. Then they meet with the nephrologist. Follow-up: The follow-up is individualized depending on needs. Frequency varies based on needs and how frail they are. End-of-life transition: Eventually, as people decline, they transfer to our home palliative team. When patients get to the point where they are bed-bound and they're unable to make it to their appointments or to our clinic, we transfer the whole chart over to home palliative who visit them in their home, which is a nice transition.
British Columbia BC Provincial Renal Agency – Conservative Care Pathway Provincial Standards and Guidelines(BC Provincial Renal Agency (BCPRA), 2016) http://www.bcrenalagency.ca/resource-gallery/Documents/BCPRA%20Conservative%20Care%20Pathway%20Guideline.pdf	Describes type of care to be provided at different illness stages, but doesn't specify staffing model. Recommendation #1: Utilize a 5-phase framework in conceptualizing the provision of care to patients on the conservative care pathway. Care provided in the Kidney Care Clinics (KCC) can be thought of in 5 phases. Phases 1a and 1b are similar for all patients irrespective of their selected modality. The other phases will vary according to the patient's modality selection (PD, HD, transplant, or conservative care). All KCC Patients (irrespective of selected modality) Phase 1a: CKD Stage 3 - 4 Care (active KCC care) (eGFR >25) • Orientation to KCC; education about kidney disease, health maintenance, and resources • KCC interdisciplinary team assessment; goal-setting and treatment planning • Introduction to advance care planning • Information on substitute decision-makers (SDM) • Discussion on what is important to the patient (i.e., beliefs, values, and treatment preferences) • Familiarization of the patient with the concepts of goals of care • Active monitoring, treatment, and psychosocial/emotional intervention as required Phase 1b: CKD Modality Selection (CKD progressing and/or anticipated to progress and eGFR 15-25) • Education about modality options appropriate to the patient (PD, HD, transplant, and conservative care) • Discussion re: goals of care within the context of modality selection (illness trajectory, prognosis, and expected outcomes) • Selection of preferred modality and documentation in PROMIS

	Patients on the Conservative Care Pathway Phase 1c: CKD Stage 5 Care (ESKD) (ongoing supportive care, eGFR <15) • Communication of patient's modality choice with patient's primary care physician (PCP) • If patient open to same, continue review and discussion of an advance care plan • Continued discussion re: goals of care, including continued desire for conservative care • Comprehensive symptom assessment and management (using the modified ESAS and symptom management algorithms) • If patient in agreement, confirmation that referral sent to home care/home support, if required • Medication/blood work rationalization • Crises education and planning, as appropriate (in case of acute worsening of symptoms, caregiver overwhelmed, etc.) Phase 2: Decompensation (life expectancy: <8 months) (declining eGFR & symptoms that would otherwise have triggered RRT if the conservative care path had not been chosen) • Communication with PCP and other patient supports (e.g., home care and/or palliative care team) re: significant changes in patient status • Continued discussion regarding current care plan, including goals of care and continued desire for conservative care • If patient in agreement, confirmation that referral sent to palliative care team and application submitted to BC Palliative Care Benefits Program • Comprehensive symptom assessment and management • Medication/blood work rationalization • Crises education and planning, as appropriate (in case of acute worsening of symptoms, caregiver overwhelmed, etc.) Phase 3: Increased Symptoms (life expectancy: <1 month) • KCC team available to PCP and hospice/ palliative care teams for consultation (mostly symptom management) Phase 4: Decline/Last Days • KCC team available to PCP and hospice/ palliative care teams for consultation (mostly symptom management)

	Phase 5: Death & Bereavement • Bereavement support • Reflecting upon the patient's death as a KCC team
Southern Alberta	Four multi-disciplinary clinics (two in Calgary, one in each of two smaller cities) that include nursing support, dieticians, pharmacists, social workers, and a nephrologist. Staffing at one clinic consists of a .6 conservative care nurse, an RN, with considerable training in communication and palliative care. An additional .4 nurse also involved. Patients are referred by their nephrologist into the multi-disciplinary chronic kidney disease clinic. Then they participate in education about the different treatment types for advanced kidney disease. Individuals who go through that education and decide that they are not interested in dialysis and have indicated that they'd be accepting of a palliative approach and somebody has embarked on at least a preliminary discussion about what their goals of care are enrolled into the program. The nurse spends a lot of time figuring out what the individual's goals are and sorting out their wishes like where do they want their care to take place, do they want resuscitation, what are the important things? She then does an assessment of symptoms using IPOS renal. She proposes a plan for symptom management. We use a checklist for the process. A lot of time is spent on investigation and medication rationalization. For lab tests, rather than just having standing lab tests, we arrange lab tests in accordance with what the person wants. We spend a lot of time on the logistical aspects related to planning for someone's death like where do they want their care to take place and how that would unfold. When individuals start to deteriorate, transitioning over to our equivalent of hospice care. Patient base is currently 50 out of 1,000 patients - about .5%, which is lower than planned for. We know there are a large number of people with low GFRs who aren't ever referred to nephrology and are followed outside of nephrology. For those under nephrology care, referral to the multi-disciplinary clinic based on a GFR of less than 15, having gone through formalized education about treatment options and chosen conservative care, desiring a palliative approach, and have had some engagement in a discussion about goals of care. Another nurse in the clinic provides modality education. She does this in group sessions and 1:1. We found that the majority of individuals are not appropriate for group sessions because they're older and they have multiple medical issues, so she really does a 1:1 education session with them. Sometimes, but not often, we provide home-based education.

	Just starting to use a decision tool about home versus other types of dialysis – the decision tool about conservative care that was developed by the group from Ottawa. There are nephrologists on call 24/7. I find most of these individuals, once they get to the point where they're deteriorating, they have access to 24/7 call through the hospice service. Prior to that, there is a nephrologist on call but I haven't found that anyone's ever really gotten in touch with the nephrologist on call.
United Kingdom Unpublished final report on a survey of all UK renal units to determine if and how they delivered conservative care. Published article provides overview, but additional perspective provided by expert panel contributor. (Roderick et al., 2015)	Sixty-seven of 71 renal units completed a survey about conservative kidney management (CKM). Although terminology varied, there was general acceptance of the role of CKM. Only 52% of units were able to quantify the number of CKM patients. A wide range reflected varied interpretation of the designation "CKM" by both staff and patients. It is used to characterize a future treatment option as well as non-dialysis care for end-stage kidney failure (i.e. a disease state equivalent to being on dialysis). CKM needs clearer classifications and definitions There was large variation in the scale and model of CKM delivery. In most, the CKM service was integrated within the service for all non-renal replacement therapy CKD5 patients. A few units provided dedicated CKM clinics and some had dedicated, modest funding for CKM. Some had funding, some included it in the role of the pre-dialysis nurses. Some had palliative care teams involved, some didn't. Informant has developed classification into three models: 1. Renal supportive care driven by palliative care specialists, but then supported by renal teams. 2. Jointly provided by palliative care and renal 3. Provided by an individual within the team who has received a little bit of training. Likely without any extra funding. Many questions within the model about best way to collaborate with specialty palliative care, GP, and renal teams. Respondent's practice when referred to specialty palliative care was to do a joint visit with the palliative care nurse. Also offered home visits by nephrology nurse. (Respondent 3)
London	This is an approach to supportive care that puts it in the geriatric framework so we can get in earlier and we can do a broader range of interventions, not just the conservative care. The thing that bothers me about just focusing on supportive care and conservative care is that you're just

	focusing on the dying. You're not actually trying to improve things. Focusing on frailty by thinking about it as a geriatrician actually tries to improve things beyond just symptom control. Currently funded for one nurse for 18 months. Using a very senior nurse with years of renal experience. For project, she received two months training from our geriatricians on how to do assessments, spent time in dementia clinic, spent 2-3 weeks with the palliative care team, a week in a hospice, etc. This gave her much better networks and then she created her own modified geriatric assessment. We introduced this geriatric approach into the peritoneal dialysis (about 100 patients) and one of our hemodialysis units (about 150 patients). She screened everybody over the age of 70 and everyone over 60 whom the local nurses deemed frail. She has identified huge levels of cognitive impairment, frailty, falls, etc. and has referred them to physios, community, falls clinic, memory clinics, social services, palliative care where appropriate, etc. There has been a huge improvement in satisfaction scores and distress thermometer scores. Also a large reduction in hospital lengths of stay. (Respondent 9)
England (Respondent 4)	We began with a multidisciplinary team entrusted in driving this forward. We called it a supportive and palliative care service because we went to our patients and asked them what type they preferred: A palliative care service, a conservative management service, or a supportive care service. Initially it became known as a supportive care service. They didn't like the palliative title, but over time it's become known more as a supportive and palliative care service. I saw the first conservative management or supportive care patient and did an initial assessment, looking very much at his social environment and the decision making. Then in terms of physical assessment of the patient, a consultant nephrologist came and did that with me. The team is nurse-led. There are two nurses, and they have advanced nursing skills so they do prescribe and they do do nursing assessments. We developed a home service as well because we started to realize that some of these patients found it very difficult to come to the hospital. But that has been very difficult to continue, and has been discontinued at the [institution] because they now have a hundred patients whom they manage within that service. (Respondent 4)
NHS “Getting It Right” report. (Boddana, P., Husbands, 2012)	The idea of introducing renal palliative and supportive care into nephrology clinics, becoming much more widespread, but it happened quite slowly. Every setting and site has done it differently, but the common features seem to be

NHS Kidney Care. Getting It Right: End-of-Life Care in Advanced Kidney Disease. London: Department of Health; 2012.	• Identifying people who can lead the work • Identifying the training needs of the wider nephrology team • Putting in place some guidelines or some resources around symptom management • Beginning to raise awareness amongst the team that some of these patients are quite close to death, maybe in the last year of life, and then they need to really address some of the issues Around 2009/10 NHS Kidney Care put out a call nationally for three pilot sites to test how you could a build a renal supportive and palliative care service. At our site, we have a nominative nephrologist with responsibility for leading this area. We also have a dedicated consultant nurse who leads in this area, and she has dual-training in nephrology and palliative care. She runs a mixture of clinics where people can attend and get problems resolved, but she also does outreach into some of the local community-based clinics, and some home visits. She draws on the renal nurses who had additional supportive care training to support this work, but she actually leads it. Patients are referred when they make a definitive decision for conservative management, and they also get referred when they are on dialysis but are either considering discontinuing dialysis or developing high symptom or other palliative concerns. There has been a shift towards patient-centered symptom burden and the concerns that people themselves report, whether it's practical issues, whether it's functional and mobility issues, whether it's family support needs, and so forth. With that shift, is it that palliative care needs to step up to the mat and do more? Or nephrology? Or primary care? And actually, it's a combination. And it needs people to work together in a coordinated fashion. So mostly, they are now more coordinated, more communicative, but bearing in mind that most of the family physicians don't see enough people with ESKD to give them enough experience in how to manage. So you have to have it quite front-loaded with nephrology and palliative care support. We've also had the experience that the palliative and hospice services sometimes haven't had the experience of nephrology. So they don't know how to manage somebody when they're receiving dialysis, or when they've got ESKD, and there has been a whole learning experience for palliative and hospice services to get the confidence to manage those things. And the places where it works really well are where the service works well together. We conducted training with nephrology staff in both symptom management and communication skills. We tried to skill up the nephrology teams in order to give them the confidence to manage a

	lot of the more straightforward problems themselves. And I think we were highly successful here at doing that. We found that of all of the dialysis patients who were identified as having higher levels of symptom and palliative concerns, about 7% were referred to the specialist palliative team. Maybe 40-45% were being managed actively by the nephrology team by adding in different things than they would've previously done. (Respondent 1)

TABLE 5: ELEMENTS OF KIDNEY SUPPORTIVE CARE

SERVICE	COMPONENTS OF CARE DELIVERY	EXAMPLE QUOTES
GOALS OF CARE DISCUSSIONS	• Engaging in discussion with patient and family to find out their preferences and goals • Documentation of goals • Some use a formal guide; others conduct very individualized conversations • Varies as to who conducts the conversation; usually nephrologist involved; nurse may also be part of it; team effort • Prognostication is necessary part of goals of care discussion process • Implementation of services to meet patient goals takes many forms • Development of detailed plans to meet patient goals,	• “So, I have a form which has everything on it. It has their clearance data, it has a summary of their hospitalizations over the last year, what their latest blood results are. So it's a one-sided bit of paper, and then there's a little box saying 'discussion,' and I just sort of summarize the things I've spoken about like discussed, you know ... Patient aware that high risk of cardiovascular disease. Or whatever. Or dialysis going well, good residual kidney function. You know, just bullet points. And then recommendations. And then there's another box which says 'advance care planning.'” (Respondent 9) • “I will tell you that the most important part is actually the conversation between the nurse and the patient. And I think we more delegate to the nurse's clinical judgment how to have the conversation, then to rely on a handout.” (Respondent 11) • “I do think the social worker and nurse play a key role talking about advance care planning and stuff. But, when it comes to actually talking about developing a healthcare plan and figuring out the goals of care, I find that the patients do have a lot of questions for me like ‘what happens if I choose this? What can I expect?’ I think a nephrologist needs to talk about that. They're definitely helpful. I think it's a multidisciplinary thing.” (Respondent 15) • Nephrology resident: “While of course I've joined a lot of conversations in the last couple of years already, what they do is they start discussions and they discuss it openly and I think this is one of the main achievements I think of the nephrologists working here. It's a topic, which can be discussed so not only, which type of dialysis—PD or hemodialysis and all those categories—but also do you really want to start dialysis. This is an open discussion I think in almost all patients.” (Respondent 16) • “You need to have prognostic studies that give you accurate survival data so that you can actually prognosticate for people to help them make decisions.… You have to have that baseline data because when people ask you, you have to be able to answer...USRDS and UK Renal Registry and the Canadian Organ Replacement Register (CORR) in Canada, those national registries are gold. They tell you if you're 80, starting dialysis, and you have diabetes, your median survival is 18 months. That's it.” (Respondent 14) • “What happens is the nurse goes through and spends a lot of time figuring out what the individual's goals are and sorting out their wishes like where do they want their care to take place, do they want resuscitation, what are the important things? Do they have important events in their lives that they want to try and reach like a wedding or do they want to travel somewhere?” (Respondent 12) • A lot of time is spent on investigation and medication rationalization. Some people call this de-prescribing but what we try and do is go through all the medications that a person is on and to figure out if they actually are in line with the person's goal and then the investigation. Rather than just having standing lab tests, what are the person's goals and are these lab tests in accordance with what the person actually wants?

TABLE 5: ELEMENTS OF KIDNEY SUPPORTIVE CARE

SERVICE	COMPONENTS OF CARE DELIVERY	EXAMPLE QUOTES
	including plans for end of life	We spend a lot of time on the logistical aspects related to planning for someone's death like where do they want their care to take place and how that would unfold. (Respondent 12)
ADVANCE CARE PLANNING PROCESS	• ACP discussions held as routine, regular part of care • ACP discussions appropriate BEFORE starting dialysis • Who conducts ACP varies by settings; in some places it is the social worker, in some places the nephrologist. • ACP part of a continuing set of discussions, not one time filling out a form • ACP often intertwined with process of choosing whether or not to start dialysis	• So we included advanced care planning as part of that discussion. So I created an extra box in my form called advanced care planning. So that's when I had the discussion. And it's not a very formal discussion, you know. It just leads from talking about how they're coping with dialysis and reviewing their clearances and thinking about is personal directive working for them or should they be thinking of something else. To what their wishes would be. And I'd be recording that." (Respondent 9) • "What we're all trying to do is actually trying to talk to our patients at the point of them deciding dialysis and starting dialysis. When they're still in our clinic, we talk to them about advance care planning. The way I say it is that dialysis is a life-extending treatment so it's something that you should talk about." (Respondent 15) • "That's what we are trying to work on, particularly the dialysis patients. We are trying to talk to all of them, eventually all of them, about advance care planning." (Respondent 15) • It's, of course, not one discussion. I don't have an average for the number of discussions, but while you can imagine it, it taking time and it really depends on the patients." (Respondent 16) • "The statement that I'll usually record, - and I always read it back to the patient. I always mention who was with them. You know like a wife, brother, friend, whatever. Patient has decided that...if very ill, no longer independent, poor chance of recovery or either future independence, does not want to linger in death. I use their words. 'Wants a dignified end.' 'Does not want to be a vegetable.' I always put that bit into inverted commas. And then I repeat that each year. And obviously as things progress, the conversation can become more detailed. So I don't mention resuscitation the first time around." (Respondent 9)
ADVANCE CARE PLANNING DOCUMENTATION	• Use consistent process for formal documentation of wishes that meets legal requirements or guidelines. • All providers know where to locate	• (Canada) "On our form, it's like the equivalent of a POLST kind of thing, but on our resuscitation form they very clearly indicate that they don't want to go to hospital. If they call 9-1-1 and the paramedics go out and the paramedics see this, they'll try and deliver care in their home and they'll try and they'll start palliative treatment and get the palliative care team out to see the patient rather than transferring them to hospital. [The form is] kept by the refrigerator." (Respondent 12) • (Canada) "In the event that they do go to hospital, we have a detailed letter that explains their wishes. We have an electronic record and it's this thing called the green sleeve. They've got their goals that we call their goals designation where they say they don't want resuscitation and they want to be made comfortable.

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	information in EMR, or in a folder, or on the refrigerator.	We've got a letter that explains what conservative care is and it clearly says to give our program a call. When they see the high creatinine, they'll often call nephrology and nephrology will say this patient is conservative. They often get admitted for palliative treatment and they don't get started on dialysis." (Respondent 12) • Between 75% and 80% of patients on this dialysis pathway have got an advance care plan and that plan is put on the alerts component of the electronic medical record. (Respondent 13)
ENGAGEMENT OF FAMILY IN CARE PLANNING	• Need to engage caregiver in ACP discussions. Family empowerment important in following ACP wishes	• "But the real key that we've found is, whilst that helps, the real key is having the family on board. And we start to see those patients generally at a GFR of about 15 or so, and the median survival time is [inaudible 00:23:48] months. So it's a long time of engagement between the team and the family, and if the family is on board and they know that mom or dad is going to die from their renal disease, they know that dialysis is not an appropriate pathway for them. And then if they come in through the emergency department they will be the ones quite commonly who will be saying 'No, this is not the pathway we're going down. Don't put them on a dialysis machine.' And we've had numerous instances of that now where the family has kind of been empowered to tell the physician that they haven't met before that this is not an appropriate line of treatment for them." (Respondent 15) • "In order to have that advance care planning, we need to have that survival and prognostic data. We need family buy-in. It always goes better if there's family buy-in. We need to include the family in the appointments or in the phone calls or at least reach out to them or give the patients written notes or somehow make sure we're not just doing it with the patient themselves. Or, if they want it to be mostly with themselves, cueing them by saying "this is a really good thing to talk to your family about. Not, are they on board with this or not on board, but what do they know about what you want?" That's actually one of the components of the Serious Illness Conversation Guide out of Ariadne Labs. (Respondent 14) • For example, what do we do with family? How do we discuss this with the family as well or if there are conflicts or et cetera. (Respondent 16) • "I find it the most difficult area because you've got the expectations of the relatives. I think it's easier if somebody is becoming demented and they're not yet on dialysis. Then you can have discussions about is dialysis really appropriate. And how it's going to make dementia much worse. And I think it's really important that you have ceilings of care written into the contract with relatives right at the start. But even then you can run into difficulties." (Respondent 9)
SYMPTOM ASSESSMENT & MANAGEMENT	• Use standardized symptom screen at each visit. (Often IPOS-renal)	• "You know I ask them how are you doing and they'll say just 'I'm fine.' And symptoms? 'No, I'm, good.' Whereas that same patient when they're filling out the IPOS symptom survey in the waiting room before the renal supportive care clinic, they might have seven or eight symptoms." (Respondent 13)

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SERVICE	COMPONENTS OF CARE DELIVERY	EXAMPLE QUOTES
	• Use algorithms to manage identified symptoms • Palliative care consultation for difficult symptoms • Attention to emotional and spiritual concerns and quality of life	• "[After discussing goals of care, the nurse] goes through and does an assessment of symptoms. We use the IPOS-renal. We use that tool. She spends time doing symptom assessments and helping come up with a plan for symptom management. I'm just pulling up my checklist." (Respondent 12) "Common features [of nephrology supportive care teams] seem to be identifying people who can lead the work, identifying the training needs of the wider nephrology team, putting in place some guidelines or some resources around symptom management, and beginning to raise awareness amongst the team that some of these patients are quite close to death, maybe in the last year of life, and then they need to really address some of the issues." (Respondent 1) • "So we're using [IPOS] as an assessment tool and an outcome measure. So for example, where I work in X, it's standard that it's used to assess the sort of palliative and symptom concerns. And we use it alongside EQ-5D, the 5-level version. Which is very brief, but it gives the sort of overall quality of life measure, and it also allows you derive QALYs. So it's very useful. So we use both EQ-5D, IPOS Renal, and then we get a kind of picture of what's happening to supplement and measure what's going it. So it supplements the assessment. And it then allows you to monitor the outcomes." (Respondent 1) • "There's been a shift towards thinking much more about the patient-centered symptom burden and the concerns that people themselves report, whether it's practical issues, whether it's functional and mobility issues, whether it's family support needs, and so forth." (Respondent 1) • "So, as people sat in the dialysis units filling in the questionnaire, they'd chat to each other and they all wanted to fill them in. So we said, 'Okay, let's just do everybody.' And then we'll know where they all are, and we could just see who needs help. And so we got everybody scored on that basis, and that's why I'm talking to you about the proportions that ended up having issues identified, which was about 40-45% by the team, and another 7% who went to the specialist palliative services because they had complex problems or symptoms or issues. (Respondent 1) • [For} symptom assessment and management - Routine use of some kind of tool. We use the ESAS…and again the PROMIS database that's provincial is plumbed or set up to accept that data… I have to say it's quite clinically helpful for me. It actually speeds up my clinic when I don't have to go through and ask about each of those symptoms. It's pre-done for me. I can look and get a very good Gestalt sort of quick snap symptom snapshot from the completed ESAS…I still have a paper ESAS." (Respondent 14) • "That's the formalized routine integrated into not only the culture but the actual function of the clinic. When you walk in the door, the receptionist says, 'Hi, Mr. Jones. Nice to see you again. Come on over here. We're going to take your weight. Here's the symptom form. Can you have a seat and do that and then next you're going to see the nurse and the nurse is going to take your blood pressure and talk to you and

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		make the notes and then next you're going to see the dietician and then after that you see the social worker and then after that you see the doctor.' If that's the order or not. It's very much protocolized. Symptom assessment and inquiry are part of the care. Then I would say having skill at managing those symptoms in renal patients is obviously really important." (Respondent 14) • "The [provincial agency] actually has four algorithms for the most troublesome symptoms: pain, restless legs, insomnia and pruritus, itching. That's where the pharmacists have come in. Provincially, the renal pharmacists on that committee have gone through the literature and work with one or two clinicians I think but it's primarily pharmacy-driven to say here's what the evidence says about each of these drugs in terms of managing this pain. Then it's also something we can send to the family docs as a resource because the family docs are notoriously anxious, understandably, about prescribing in renal patients because they're afraid of ... 'I don't want to do anything that's going to give them too much or maybe it's contraindicated or it's going to give them some crazy side effect.' Having that as a resource is really helpful because it actually strengthens the GP's role in this team." (Respondent 14) • "This is the symptom management binder. It sits on the physician's desk. There are tabs for each of the algorithms. There's a one pager overview for pain in tiny print with then like a 30-page guide for all the specifics. Same thing, there's a pruritus/itching one. There's a restless legs one and then there's an insomnia one." (Respondent 14)
SCREENING AND REFERRAL FOR SPECIALTY PALLIATIVE CARE	• Referral guidelines that distinguish renal palliative care service from specialty palliative care service	• "People were confused in the hospital as to when they refer to specialist palliative care and when do they refer to the renal palliative care service, and what was the difference? We wrote renal palliative referral guidelines to help with appropriate referrals." (Respondent 3)
IN-HOME CARE SERVICES	• Flexibility to provide visits and services at home	• "I do think there is something about that home connection that bridges a gap that we as medical providers just don't usually bridge. At that point in a person's life, it's just a very powerful thing. You know? I think it's just meaningful for them. We're acknowledging that it's difficult for them to get around at that point. You're acknowledging to them that their home and family are important to them. I don't know, you're just kind of affirming a lot of things by doing that home visit. (Respondent 5)
PALLIATIVE DIALYSIS & OTHER DIALYSIS OPTIONS	• Assisted peritoneal dialysis • Palliative dialysis	• [Assisted PD] keeps your frail, older people in their own communities. It can keep them at home, it can keep them in nursing homes, residential care. (Respondent 9) • I'm an advocate of palliative dialysis. My view is now, even if you have comorbidities and we don't think you'll do very well on dialysis, if a patient really wants to give it a go, then I think we should be able to tailor dialysis more. And that might be less sessions, it might be a very clear understanding that this is

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		palliative from the start, that it will be reviewed… possibly a trial of dialysis. In the past, if a patient wanted to have a trial of dialysis, my experience was we never reviewed them, and people would just end up dying on dialysis. So I'm quite into that concept at the moment. It's not clear cut who should have it and who should not. And if people want to try it, they need to have quite heavy palliative and supportive care alongside it." (Respondent 3)
DIALYSIS WITHDRAWAL	• Established process to respond to patient's desire to stop dialysis. • Managed transition to hospice or PC support. • Need to manage difficult symptoms	• "For dialysis withdrawal, we've actually not been doing too badly. We've established a process so they don't actually have to go to the hospital. If a person starts expressing that they're tired and they don't know if they can do this anymore, we have people who are willing to talk to them and then we get the palliative and hospice team involved and then the person doesn't even have to go to the hospital. It's all done through the dialysis unit and then they palliate at home or in residential hospice." (Respondent 12) • "I witnessed a number of really difficult dialysis withdrawal deaths… and if you read the literature it presents dying following dialysis withdrawal as a 'good death' and relatively asymptomatic. I think with hindsight, this evidence relates to when people were dying from uremia per se. I think now we are caring for a very different population, older, frailer and with a high prevalence of symptoms from their co-morbidities rather than their renal disease. " (Respondent 3)
OUTCOME MEASURES	• Need to collect data to show impact, need clear outcome measures	• "Place of death… are they dying at where they want to die? And what point in time do they get followed by palliative?" (Respondent 15) • "We've been sort of keeping track of patients' comments, testimonials, that kind of thing, too." (Respondent 15) • "The measures we chose at the outset were advance care planning, like was it initiated? Did they have their form filled out? Was the preferred place of death known? What was the match between their preferred place of death and their actual place of death? Death in hospital. The dialysis quality of dying APGAR and then bereavement follow-up. Did they have the phone call and the information sent out?" (Respondent 12) • "What came out from [focus groups with current patients and families] was that dying peacefully was very important, having a key contact in the conservative program and having team members that have gone through training in conservative care were like the top three things that they identified in those focus groups." (Respondent 12) • "We kept all of the data on that [early pilot program] and again there was an improvement in symptoms and improvement in family satisfaction." (Respondent 15)
END-OF-LIFE SUPPORT	• Need to transition to hospice/ palliative care in community	• "You need to know [the hospice and palliative care resources] in your own community because you need to know.... You probably shouldn't do all the details of how to plan a home death and the real nitty gritty of what equipment you need and an emergency med kit and all that stuff." (Respondent 14)

TABLE 5: ELEMENTS OF KIDNEY SUPPORTIVE CARE

SERVICE	COMPONENTS OF CARE DELIVERY	EXAMPLE QUOTES
	• Plan for end-of-life phase – both handling logistics and meeting patient preferences	• "We spend a lot of time on the logistical aspects related to planning for someone's death like where do they want their care to take place and how that would unfold. When individuals start to deteriorate, transitioning over to our equivalent of hospice care." (Respondent 12) • "What we usually find is that the individuals are pretty stable, they might have their ups and downs but they lose their appetite, they stop eating and then they become bed-bound. When that occurs, death is imminent within days and we need to ramp up end-of-life care really rapidly. It seems to be a cliff they go over. Everything has to be ready so when they start to tip over it all can be ramped up very quickly. We have to have all the forms filled out. We usually get the hospice team to meet them in advance, and not necessarily do a lot of care, but they're in their system, they're register and then the palliative care team know when we call and we say we've got someone deteriorating that that person will likely die within days, and they need to get to see them right away and make sure they have the adequate services in place. It often happens quite suddenly. They're doing okay and then they start to change." (Respondent 12) • "I'll refer [to hospice] when I have a conversation that I wouldn't be surprised if something happened. And I think that there are either symptom control needs, social things like needing hospital beds, I mean all those things are much easier to organize if somebody can say they're in the last six months. You can get, there's much better community support. If I feel that the relatives need some support themselves, I often present it to the family as being extended care in the community." (Respondent 9)

TABLE 6: ELEMENTS OF CONSERVATIVE CARE PATHWAY

SERVICE	COMPONENTS OF CARE DELIVERY	EXAMPLE QUOTES
IDENTIFYING POTENTIAL PATIENTS	• Confirmation that referral aligns with patient preference. • Use of a variety of prognostic factors including frailty to inform both provider and patient. • Good data needed for individualized prognostication.	• "We early on just accepted a referral from a nephrologist or one of the nurses but what became apparent is that they perhaps thought they communicated with the patient and their family, but what the patient took away from there wasn't clearly that they were choosing not to do dialysis. That's why we actually insist that they have to go and have the proper education and listen to the different options that are available, and then at the end of that make decision." (Respondent 12) • "We discuss any of the patients with GFR below 15 who are heading towards end stage kidney disease pathway. And if anyone is over 75 we have a mortality discussion as to in case what are the comorbidities, functional status, nutrition, etc. And that's proving to be really quite helpful because it's allowing us to discern, okay you are over 75 but you're actually quite okay in many respects and dialysis is appropriate, or the converse. So, that's proving to be a useful tool as well." (Respondent 15) • "We started doing a frailty assessment for all patients 70 and older, in our [inaudible 00:18:40] transitions clinic. The plan is to do that on a quarterly basis just to kind of see how needs change." (Respondent 17) • "Accepting into an RCT of conservative care people over 80 and people over 65 with WHO frailty score 3 or more and GFR under 15." (Respondent 6)
REGISTRY OR CLEAR TRACKING OF PATIENT MODALITY	• Track modality plan • Clear identification of patients who have chosen conservative care and those who have not yet decided.	• "Every Monday I get a list of people who have a GFR under 15 and what their modality plan is." (Respondent 14) • "We have supportive care registers here. It was encouraged probably about five or six years ago, we had a national service framework which included end-of-life care, so we were all encouraged to build supportive care registers in our renal units. And to ask the surprise question and if you answered no to that, you were meant to try and have a conversation with the patient. And then you would record those conversations on a screen so that when the renal resident or whatever you want to call them was called ... Mrs. Jones in the middle of a night or on a Saturday or Sunday, they always have access to the renal IT system when they're on their phone. So they go, 'Oh, she's made a decision she doesn't want dialysis.'" (Respondent 6)
SHARED DECISION MAKING	• Education for patients that includes unbiased information about conservative care.	• "The renal nurse gives presentation. They use a PowerPoint presentation in their discussion with patients and family. In that presentation is information about all forms of dialysis including the option to not start dialysis, which is also gaining more information, of course, while research is going on that particular topic. We also offer the opportunity for a visit to the dialysis clinic to see the machines, to see patients on it. It's really up to the patients." (Respondent 16)

TABLE 6: ELEMENTS OF CONSERVATIVE CARE PATHWAY

SERVICE	COMPONENTS OF CARE DELIVERY	EXAMPLE QUOTES
		• "I will tell you that the most important part is actually the conversation between the nurse and the patient. And I think we more delegate to the nurse's clinical judgment how to have the conversation, then to rely on a handout." (Respondent 11) • "I think every nephrologist is different so I can't speak for all nephrologists because I think some of them are more comfortable about talking about it than others. Certainly for me, I end up doing a lot of the talking with the patients. When it comes up to dialysis in one of the patients who has multiple co-morbidities, I talk about conservative management. I spend time talking about [inaudible 00:13:19] care and all that with the families…. We do have a couple of tools that we use. We have a hand out that we give to patients about conservative management." (Respondent 15) • "Then they participate in education about the different treatment types for advanced kidney disease. Individuals who go through that education and decide that they are not interested in dialysis and have indicated that they'd be accepting of a palliative approach and somebody has embarked on at least a preliminary discussion about what their goals of care are are enrolled into the program." (Respondent 12)
MESSAGING AND EDUCATION	• Conservative care is active medical management – you continue to be cared for by nephrology team, just not using dialysis as a one of the treatment options. • Palliative care/hospice about quality of life, not just very end of life.	• "One of the most frequently asked questions to us is, how do you educate patients on this or how do you talk about this? When they started here doing those discussions, the renal nurses especially, were concerned from how do you frame it and aren't you preventing us from doing our work because you are not giving us dialysis patients. I think the way it is framed here is conservative care is ongoing treatment here with the same team so also the renal nurse, dietitian, and social worker are involved if necessary. Everything stays the same and we try to do as much with medication, diet, to prevent having symptoms and delay deterioration…to make very clear and reassure that the nephrologist remains your nephrologist and you are allowed to be seen here in the hospital [clinic]." (Respondent 16) • "Because I came from a health psychology background where I understood that patients are not doing nothing. They're actively managing their kidney disease. That is an active kidney option. An active treatment option. It was very clear to me from my perspective. It was not doing nothing or not having an active option. But how do you raise the profile of the conservative care option so that it was equivalently active? That's where my decision-making side came in. Because I was very aware that the language that was used was very biasing and switches people off." (Respondent 7) • "We've done … education at the point of the kidney diagnosis on what disease trajectory looks like understanding the difference between life support and a bridge to cure." (Respondent 2)

TABLE 6: ELEMENTS OF CONSERVATIVE CARE PATHWAY

SERVICE	COMPONENTS OF CARE DELIVERY	EXAMPLE QUOTES
		• "The enormous care I have when I use language with patients - And I'd like to think that has also filtered through to the team and the predialysis nurses are now very, very good at getting that decision right, particularly for conservative management." (Respondent 8) • "We do have a clinic for people with advanced CKD but it's called a pre-dialysis clinic, so that kind of gives you a hint of kind of how everything was approached in this clinic… I always hated the perception of pre-dialysis, because that's what people had on their appointment card. People would be afraid, they'd run away because of all of this."… [Interviewer:] "Will you change the name?" [Respondent:] "Oh God yes. Yes, that's the first thing on the agenda. I'm thinking of Kidney Transition Clinic." (Respondent 17) • "In my short hand I use MCM because that's what Dr. in London was using. Maximal conservative management, which I think they use to sort of mitigate this worry on families who say you're going to do nothing." (Respondent 14) • "Yeah. So we're using [palliative care] for much longer than that. At least I am. So yes, there is some resistance from my patients. As soon as you mention palliative care, they think death is imminent. But I always, you know, soon as I mention palliative care or hospice, I say, this doesn't mean... Hospices and palliative care are not end of life. It's supporting you in this final phase of your life to make things as good as possible." (Respondent 9)
SYMPTOM MANAGEMENT AND QUALITY OF LIFE	• Symptom management • Although can be long periods where symptoms are minimal, need to be prepared to ramp up quickly when symptoms escalate, especially at EOL	• "That's one of the aims of the [conservative] care, that we do actually assess and manage symptoms, but we also do some of the things that we do with pre-dialysis patients, to help potentially slow the progression of renal failure. We can still give them ACE inhibitors and phosphate binders, although you could argue, 'What's the benefit? And what are the outcomes for patients, whether they have that or not?' I don't know. There is still little evidence regarding interventions and outcomes in this population." (Respondent 3) • "Everything stays the same and we try to do as much with medication, diet to prevent having symptoms and delay deterioration [inaudible 00:21:11] but also quality of life and et cetera." (Respondent 16) • "A lot of time is spent on investigation and medication rationalization. Some people call this de-prescribing but what we try and do is go through all the medications that a person is on and to figure out if they actually are in line with the person's goal and then the investigation. Rather than just having standing lab tests, what are the person's goals and are these lab tests in accordance with what the person actually wants?" (Respondent 12) • "What I realized quite quickly, particularly the people that had multi-comorbidities and were frail who deteriorated rapidly... they didn't need a line inserted and dialysis, they needed really good

TABLE 6: ELEMENTS OF CONSERVATIVE CARE PATHWAY

SERVICE	COMPONENTS OF CARE DELIVERY	EXAMPLE QUOTES
		palliative care. They needed good symptom control, they needed hospice care, psychological and family support. Crucially, they needed someone to have brave clinical discussions with them. I really like the concept of clinical bravery. I believe it is easier to insert a line in someone and start dialysis than it is to have those discussions around, 'This still isn't the right thing for you. And what we really need now is really good symptom control and palliative care support.' Many of these patients are dying and dialysis won't make them better, in terms of survival, symptoms or quality of life. We need to recognise these patients and have brave clinical discussions to make shared decisions about their end of life care" (Respondent 3)
CARE PLANNING AND CONTINUING MANAGEMENT	• Care planning • Preparation for end of life	• "It's really been a lot of advance care planning and care planning and a lot of discussions about goals and trying to figure out what people want and ensuring that their care is in line with those goals. A big part of what happens is really reviewing goals and choices, making sure that their resuscitation status is documented and the appropriate forms are filled out, making sure that there's a crisis plan in place and that there's time to do death preparation, assessing their spiritual needs. We spend a lot of time educating the family and the caregivers about what to expect." (Respondent 12) • "The introduction of the palliative care team to the patient at an early stage [is what makes it better] so that they have ideally, what works ideally is when they've perhaps done a home visit and met the patient and said, 'Hello, my name is John and I'm from the hospice and we don't need to ... tell me a bit about yourself, what did you used to do? And what's your dog called and that sort of thing. And then I'll tell you a bit about the hospice and you don't need to have anything to do with us. You may never need to have anything to do with us. But ...' So that, you know, that visit, and then they leave a card so that people know, so that the husband or wife knows how to get in touch with them. That's what works for us locally. When it has worked well, that's when it's worked well." (Respondent 6)
TRANSITIONS TO END-OF-LIFE CARE	• Managed transition	• "The follow-up, again, is individualized and depends how often they come, how frail they are. Eventually, what we find is that as old people decline, they end up transferring them over to our home palliative team, which is very nice. They get to the point where they are sort of bed-bound and they're unable to make it to their appointments or to our clinic, we transfer the whole chart over to home palliative who then go visit them in their home, which is a nice transition." (Respondent 15) • "So I would refer these patients to the hospice or the palliative care in the community, and they'd go and see them, and they'd come and say, 'Well there's nothing for us to do, they don't have any palliative care needs.' ' A common occurrence was the community palliative care teams would discharge patients. In my experience these patients may stay stable and relatively asymptomatic but

TABLE 6: ELEMENTS OF CONSERVATIVE CARE PATHWAY

SERVICE	COMPONENTS OF CARE DELIVERY	EXAMPLE QUOTES
		would deteriorate and die quite quickly. So we learned early on that we needed to explain to palliative care teams, ‘Actually, they may be relatively asymptomatic of uremia but patients managed conservatively without dialysis can deteriorate very rapidly. This means you need to meet them much earlier on in their illness trajectories in order to anticipate that “tip.” The clinical implications are that you need to have a responsive and sort of flexible service for this group of patients.’" (Respondent 3) • [interviewer:] “Do you notice anything in bereavement that you think is particular to the patients in the conservative management program? Not to the patients but to the family members?” [Respondent:] “I think they're more prepared. We talk a lot about anticipatory grief and there are a lot of opportunities to help people leave a legacy. I feel like when people go through our program, there's not that abrupt end to things. This has been a journey, not so much an all of a sudden it's over kind of thing.” (Respondent 12) • “They'll [hospice nurses] make an initial [home visit] contact and assessment. And if the patient has just got a few minor symptoms, death isn't imminent, they won't necessarily schedule another visit. But they'll leave contact details with the family and the patient. And then contact will get more as needs determine. So sometimes it's people going up as outpatients to the hospice and taking use of the things that the hospice offers in terms of ... Some hospices offer things like physical therapy, social clubs, you know, acupuncture and various other things. And there's obviously a bit of respite care for the relative as well. Sometimes it's just symptom control or whatever. And then they get more and more involved until the last, you know, with anticipatory prescribing at the end of life.” (Respondent 9) • “We have a palliative benefits form where if you think the prognosis is six months or less, you fill out the form. They have access to just a few more resources, whether it’s a few more of their meds are covered, they can get a hospital bed without cost, that kind of stuff. You need to know about that because if you're assisting them in that transition, you need to know what's available and you need to know where's your local palliative care unit? Where's your local hospice unit? Does the hospice accept ... Do they have beds?... You probably shouldn't do all the details of how to plan a home death and the real nitty gritty of what equipment you need and an emergency med kit and all that stuff. Frankly, I don't think renal programs have the resources to do that, but you need to know who does in your community.” (Respondent 14)

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